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## The Debate on Physician-Assisted Death in the United States: A Narrative Analysis of Formula Stories

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The Debate on Physician-Assisted Death in the United States:

A Narrative Analysis of Formula Stories

by

Rebecca Blackwell

A dissertation submitted in partial fulfillment of  
the requirements for the degree of  
Doctor of Philosophy  
Department of Sociology  
College of Arts and Sciences  
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## **DEDICATION**

I dedicate this text to my father, who worked so hard to give me time to write it, and to Lala Canel and Natasha García for always being there.

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## **ABSTRACT**

Public policy discussions can be viewed as empirical windows into broadly shared cultural values and emotions of the social contexts in which the policy discussions take place. This project is a narrative analysis of the public debate on physician-assisted death (PAD), drawing from three data sources: newspaper articles, the websites of social movement organizations, and testimonies from a state legislative hearing. This analysis explores ways in which social actors deploy personal stories that contribute to shape the policy-making process by appealing to cultural beliefs and broadly shared emotions. The findings of this project constitute a contribution to the study of emotions as cultural phenomena, to the use of narrative analysis in the study of public policy, and to the adoption of constructionist approaches in the study of social problems and health and illness. A constructionist lens allows for the observation of not only differences but also commonalities in the competing narratives, helping to fill a gap in the literature on PAD, which is dominated by one-sided positivistic and critical approaches, predominantly within the areas of legal, biomedical, and disability studies.

## CHAPTER ONE: INTRODUCTION

Physician-assisted death (PAD) is often conceptualized as a “deeply polarizing” issue (Minkler et al. 2002; Messinger 2019). In the debate about this issue, cultural ways of thinking and feeling have created heated antagonism among stakeholders and in public opinion in general. Qualitative analyses on the PAD debate have explored the role of political affiliation (Kamakahi, Wilson, and Fox 1998) and ideology in people’s perceptions of the subject, and some scholars have argued that views on this “moral issue” are strongly tied to “the culture war in the United States” and that the issue of PAD “has helped to redefine what it means to be a liberal or a conservative” (Strate, Kiska, and Zalman 2001:156). Although recent survey data on moral issues in the United States do indeed show a divide along party lines on this public issue (Brenan 2018), the data also show that within both parties, more people find PAD morally acceptable than unacceptable.

I address this health policy issue from a constructionist perspective (Conrad and Leiter 2003) because such a perspective can give us insight into the shared meanings and emotions that inform policy processes. A primary goal of this analysis is to explore ways in which culture, policy, and narrative intersect with one another. And in order to gain knowledge on the specific cultural beliefs that are central to the current policy debate on physician-assisted death, I ask the empirical question: What do the personal stories in the debate on PAD tell us about broadly shared beliefs and emotions regarding social needs in the realm of health and illness in the United States?

This project is an effort to gain understanding on shared ideas that circulate at the national level regarding this issue, through the empirical analysis of circulating stories. The focus of the analysis is the patterns of ideas about health, illness, and health care used to justify or condemn PAD in the different contexts where the stories are used. This is an aspect of the debate that has remained largely unexplored in the literature on this subject because the academic research on PAD in the United States has used predominantly positivistic or critical approaches and has traditionally taken sides on the issue. Paradoxically, the most significant gap in the literature on this moral issue is the study of the value system operating in it. In this project, I employ narrative analysis to address this gap.

My methodological goals are to demonstrate how using narrative analysis can help us understand the underlying cultural emotions and values (Franzosi 1998) in public policy debates and to demonstrate the empirical value of publicly available data sources, such as mass media, organizational websites, and legislative archives. I use narrative analysis to explore how identities in this debate are defined in public communication and throughout various levels of social life, such as the press, social movement organizations, and legislative institutions. My approach to narrative analysis is based on narrative theory that proposes that human communication is fundamentally structured in the form of stories (Fisher 1984).

To attain these goals, I analyze the “patterned dimension” of stories (Gubrium and Holstein 1998:164) used in three different contexts of the public debate on PAD over the past thirty years. The present study is thus a multilevel narrative analysis (Loseke 2019) in which I analyze how symbolic meanings are deployed through stories that travel from one realm of social life to another. I argue that the circulating plots and character types that constitute the dominant cultural stories on PAD today in the United States operate as moral guidelines for the social

actors involved in the policy-making process. This interpretive analysis of ways in which social actors connect symbolic and emotion codes in the stories they share in their public conversation about this issue shows how cultural stories can affect structural change.

In the following two sections, I lay out the theoretical and methodological boundaries of this research project. Next, I describe previous research that has, in one way or another, investigated the cultural understandings and emotions associated with this policy issue, and lastly, I state the research questions organizing the analysis and describe the specific topics and methods of each chapter.

#### EXPANDING THE SCOPE OF NARRATIVE ANALYSIS IN POLICY PROCESSES

When social policy is created, all types of social actors, including institutional powers, elites, advocacy groups, and the media, operationalize circulating cultural narratives to shape the policy-making process. Cultural narratives are those broadly circulating stories about human experience, about the way the world is or should be, that operate in our daily social communication and permeate all levels of social life. Be it in our individual, institutional, or social contexts, we live by our narratives because we create them to make sense of the world (Fisher 1984). Public debates about policies are just another instance in which our narratives, our cultural stories, become a determinant factor for our material lives, because through public policy, our narratives build and modify social structure.

To understand how narrative, through policy, is interconnected with material life, we must explore the relationship between culture and policy. Policy scholars have long noted that storytelling is fundamental to policy making and that narrative analysis is thus a key method for the study of policy processes (Hajer 2002; Fischer 2003; Roe 1994; Stone 2002). This project

addresses this methodological need and in doing so contributes to the study of emotions as cultural phenomena (Kusenbach and Loseke 2013), in turn contributing to our understanding of the cultural foundation of social structure (Swidler 1986).

The use of the narrative method of analysis in this project has helped to uncover subjective moralities embedded in the symbolic communication (Loseke 2007) of this debate, demonstrating the utility of constructionist approaches to the study of health and illness (Conrad and Barker 2010) and to the study of social problems related to the institution of medicine (Conrad and Leiter 2003; McKinlay and Marceau 2000).

In this project, I conceptualize culture as a semiotic fabric, or webs of significance, which humans create (Geertz 2000) by classifying unique phenomena into generalizable categories (McCurdy, Spradley, and Shandy 2004). Culture can also be understood as the configuration of meanings that acts as an ethical pedagogy enabling us to interact with one another inside our social groups and within the broader social structure of our time. However, our “collective self, buried within each one of us” (Eagleton 2000:7), takes for granted the cultural categories it “knows,” which is why systematic research is necessary to discern our cultural narratives.

I specifically investigate the PAD debate to explore ways in which cultural ideas travel through time and between different levels of social life through cultural narratives. I combine the concepts of formula stories (Berger 1997) and symbolic and emotion codes (Loseke 2007) with theories about the social construction of social problems (Best 2008) to explore the social circulation of broadly shared ideas and emotions. The concept of formula stories (Berger 1997) refers to dominant narratives that are broadly shared by a given community and that give moral value and emotional meanings to social phenomena. Some narratives are to some degree socially durable maps to understand experience, to morally classify the world; these narratives operate as

formula stories, that is, “scenarios” about human experience that broadly circulate through narratives in given communities.

Through this analysis, I have sought to understand how the symbolic value of stories facilitates the process of appealing to heterogeneous audiences (Loseke 2012). This function of stories is especially relevant when the social process at hand is policy making, which represents a tangible change in structural conditions. More specifically, I have sought to understand what the main formula stories in the contemporary public on PAD are and what these stories do at each level of social life in which they are used.

A preliminary review of the interdisciplinary literature on the PAD debate in the United States led to the selection of three data sources. The first data set consists of 44 *New York Times* newspaper articles from 1997. Two landmark Supreme Court cases took place in this year, and the issue of PAD had more press coverage at this time than ever before or after in the contemporary history of the U.S. (Glick and Hutchinson 1999). The second data set consists of 152 personal stories drawn from the webpages of two of the most prominent social movement organizations in the national debate: Not Dead Yet, an anti-PAD organization; and Compassion and Choices, a pro-PAD organization (Engelhart 2021; Behuniak 2011). The third set of data consists of 144 testimonies presented at a 2019 legislative hearing in Maine, one of the most recent states in the U.S. where PAD has been legalized.

This analysis revealed that there are two formula stories at the core of this public debate. The central formula story used by proponents of PAD is that of a *good death*, built around the plot of individuals staging and controlling three conditions of their own death: time, place, and company. The central formula story used by opponents of PAD is that of a *slippery slope*, built around the plot of the imminent and catastrophic abuse, due to the prevalence of social

inequality, of a policy that would give doctors the legal right to prescribe lethal drugs for the purpose of hastening the death of terminally ill patients. The analysis also revealed, however, that a single formula story may be used for different purposes in the different contexts of social life and that appeals to similar values can be made through the use of formulaic identities for opposing purposes.

This project is neither an ethical analysis nor a historical account of this policy debate. It is instead a study of the salient story lines in this public conversation that explores broadly shared values regarding health and illness and their relationship with social worth and social agency.

#### EXPANDING THE STUDY OF EMOTIONS AS CULTURAL PHENOMENA

This analysis explores the interrelationship of culture and emotion. We think about how we feel, we feel about how we think (Loseke 2019), and our actions and interactions in society are inextricably affected and ruled by this interplay between our thoughts and our feelings (Hochschild 1979; Stearns and Stearns 1985; Gordon 1990).

By exploring the formula stories in this policy debate, I trace ways in which cultural ideas and emotions are used by social actors to define life experiences as social problems in need of solutions. I argue that the narratives in these data operate as moral lessons and that the presentations of the plot vary from one context to another because the purpose of the story is not the same in all contexts. In my analysis, I found that the debate in each context focused on a different aspect of the issue. The rights of doctors, the needs of people (people with terminal illnesses and people with disabilities), and the state of the health care system are at the center of the narratives that I explored. Further data to expand this multilevel analysis could include the



views of individuals in hospice facilities, both patients and health care providers, as well as people in private homes experiencing their own terminal illness or the illness of a family member.

### *The Rights of Doctors*

The focus of the stories in the *New York Times* is the views and characteristics of physicians. The cases being discussed in the Supreme Court at the time were driven by physicians, and thus the motives and ethics of doctors are at the center of these stories. Jamieson and Waldman (2003) argue that mass media shape public opinion by presenting compelling narratives built with selected and partial information, in which appeals to pity, fear, and personal identification are frequent.

### *The Needs of People*

The stories featured on the social movement organizations' webpages focus on the lives of the types of people who would potentially use PAD to hasten their own death, either by choice, in the narratives in favor of the narrative, or by coercion, in the narratives against. Through these stories, the organizations strategically define the views and the desired values of their members and supporters. This communication strategy has been frequently observed by social movement scholars (Polletta 2006) who have studied how organizations adopt widely accepted values in their narratives (R. Williams 2007) to persuade (Entman 2003) and to share their desired mentalities (Tarrow 1992) or repertoires of ideas (Tilly 1978), thus establishing the need for action (Lipsky and Smith 1989; Snow, Soule, and Kriesi 2007).

### *The State of the Health Care System*

The stories in the Maine legislative hearing paint a picture of the structural and cultural conditions of the health care system. These narratives are used as arguments to make the case for a need for institutional solutions to a social problem that is being defined, at least in this context, through the viewpoint of caregivers for the most part. These legislative debates have led to great success for supporters of PAD in the past six years, and legislation on PAD is growing across the country (Houghton 2021). Today, PAD laws are in effect in ten states across the U.S. After Oregon, Washington, and Vermont, where PAD was legalized in 1997, 2008, and 2013, respectively, seven more states have joined: California and Colorado (since 2016); the District of Columbia (since 2017); Maine, Hawaii, and New Jersey (since 2019); and New Mexico (since 2021). And in Montana, the state supreme court declared PAD not illegal but left open the question of whether the practice is protected by the state constitution. The cultural beliefs and emotions operating at this level of the debate, where policy-making decisions materialize into laws, speak to broadly shared ideas about the institutions affected by these laws. The experience of the caregivers, nurses, doctors, and family members are at the center of these stories, which focus on the problems and solutions for issues of physical and mental health in the relationships between people and institutions.

### PREVIOUS STUDIES ON THE CULTURAL DIMENSION OF THE PAD DEBATE IN THE UNITED STATES

One way in which previous studies on physician-assisted death have addressed culture has been by exploring aspects of the issue that relate to the use of language. For example, studies in bioethics have looked at how medical professionals talk about PAD (Gerson, Preston, and

Bingley 2020), and legal studies have addressed the types of legal arguments, whether moral or emotional, used in the legislative debate and their similarities to and differences from arguments used by the medical community (Mitchell 1998). A focus on language has also emerged from the critical view of disability studies, where there is a concern for what has been conceptualized as an ableist ideological framing of the arguments in favor of physician-assisted death—in fact, the practice is only referred to in this literature as “physician-assisted suicide” (Haller and Ralph 2001; Amundson and Taira 2005; Schwartz and Lutfiyya 2009). This choice of words comments on the historical social exclusion of people with disabilities. In such a context of discrimination, PAD is described as a policy in which the chronic conditions of many people with disabilities are described as creating a lack of dignity justifying hastening death. From this perspective, hastening death because of a disability would be suicide, which is to say, an act of desperation, not a rational choice. Efforts to examine the rhetoric of social actors in this debate have explored social movements and the press. One study explored the notion of “dignity” as deployed by social movement activists (Behuniak 2011), and another looked at the use of the notion of “autonomy” in press articles on PAD (Kalwinsky 1998).

This project expands on the preceding works and on the works of political scientists (Ball 2012, 2017; Lavi 2009) who have explored the circulating arguments in the legal battles over PAD in the United States from a historical perspective, focusing on the historical development of the arguments. A broadly cited analysis was by the bioethicist Ezekiel J. Emanuel (1994). He identifies an essay called “Euthanasia,” presented in 1870 at a local club of professionals and businessmen in Birmingham, Britain, and disseminated in the U.S. through its publication in the *Popular Science Monthly* (S. Williams 1873), as the first broadly disseminated public discussion of the modern conception of euthanasia and its subcategory of physician-assisted death. Lavi,

who presents a historical view of the PAD debate from a Foucauldian perspective, makes the point that the medico-technical solution to hasten the death of suffering patients afflicted by a combination of “pain and hopelessness” (Lavi 2009:42) first appeared in this late-1800s essay and not in the 1960s as a result of the recent boom of medical advances and medical technology and the artificial prolongation of life, as is frequently argued (Hoefler 1997; Strate et al. 2001; Ball 2012, 2017; Mitchell 1998). The relevance of Lavi’s argument for this project is that it ties the PAD debate to a broader cultural framework: the “regulation of biological processes” (Lavi 2009:169).

## RESEARCH QUESTIONS AND CHAPTER DESCRIPTIONS

The overall research question that has guided this analysis has been: How do the stories deployed at the different social levels of this public debate represent—through their plots, narrative identities, and settings—socially circulating views on issues related to life and death, dignity, freedom, and the medical system? The specific empirical questions guiding the different empirical analyses are: (1) What are the predominant symbolic and emotion codes embedded in the stories about the types of people, plots, and settings associated with PAD? (2) What do the differences in these symbolic representations used at each societal level of the debate tell us about the intended purpose of the stories? (3) What could the implications of the exclusion or inclusion of elements in the predominant stories be for the overall policy-making process? I explore these questions in the context of what I identify as the natural history of the social problem of the miserable death.

## Chapter 2

In this chapter, I explore the cultural production of stories through the work of mass media, because mass media is the primary way in which stories are disseminated throughout society. I study the stories on physician-assisted death presented in one year (1997) of articles in the *New York Times*, which is commonly referred to as the most influential news organization reporting on sociopolitical developments of the United States (Glader 2017; Usher 2014) and is frequently studied in relation to significant political issues due to its intermedia influence, which is to say, the influence that one medium has on another (Golan 2006; Reese and Danielian 1998). I seek to explore ways in which the relationship between culture and emotion is situated within a specific time and place (Stearns and Stearns 1985; Lutz and Abu-Lughod 1992; Moïsi 2010).

In 1997, the year when the stories in this analysis were produced and published, the United States Supreme Court gave an opinion on its first cases about PAD: *Washington v. Glucksberg* and *Vacco v. Quill*. The newspaper articles in this analysis largely emerged in response to this judicial event, and the coverage of the debate in 1997 was related to the two Supreme Court cases as well as the trial of the controversial Jack Kevorkian, who euthanized dozens of patients outside of the clinical setting and standards of medical practices (Roscoe et al. 2001) and who was broadly featured in the publicly circulating stories on PAD in the 1990s (Kalwinsky 1998).

In this chapter, I observe the ways in which actions, identities, and events are characterized and associated with emotions (Pizzarro 2000) and the selection of cognitive information (Zerubavel 2015). My goal is, on the one hand, to gain understanding on the way emotions and ideas about how the world works and how it should and should not work are shared through the stories about human experience that circulate in a particular time and place.

On the other hand, my objective is to explore how stories on a social issue appear in one specific level of society and through what I conceptualize as one stage in the construction of a social problem.

### *Chapter 3*

In this chapter, I explore the use of stories by social movement organizations (SMOs) to disseminate the movement's values. I analyze data drawn from the webpages of two of the best-known contending grassroots organizations in the debate on physician-assisted death in the United States: Not Dead Yet (NDY), a disability SMO created to oppose the legalization of PAD; and Compassion and Choices (C&C), an SMO that promotes and defends PAD bills across the nation. Through cyber communication, the civil society groups in this analysis demark what ought to be the group's shared understandings (Fine 2012) and the group members' identity (Oyakawa 2015). To do this, the SMOs generate the emotional identification of movement members (Polletta 2006) so that they feel that their views are aligned with the views of the organization (Snow and Benford 1988).

My goal in this analysis is to examine ways in which storytelling is used to legitimize the existence of a social problem (Best 2008). I focus on how SMOs use deeply embraced and uncomplicated cultural stories with formulaic plots (Berger 1997) to present grievances as worthy of social attention, action, and structural change such as public policy (Loseke 2019).

### *Chapter 4*

This chapter examines one of the most recent state legislative processes in the United States leading to the legalization of PAD in the United States, which was in Maine in 2019. I

specifically look at the testimonies of the attendees of the last hearing on the subject before the voting session of both houses of the Maine Legislature. As in chapters 2 and 3, I conduct a narrative analysis of the cultural stories deployed in these testimonies and observe the mediation of the stories on the part of the institution where they are presented.

### *Chapter 5*

In the final chapter of this project, I discuss the general theoretical and methodological contributions of this analysis and its implications for this policy issue in this place and time. I also discuss the understanding that policy analysis can give us about dominating cultural ideas and collective emotions and suggest, based on specific aspects of my findings, what I consider are necessary future research directions.

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## **CHAPTER TWO: MEDIA NARRATIVES ON PHYSICIAN-ASSISTED DEATH: THE LEGITIMIZATION OF CULTURAL STORIES**

We create culture when we characterize actions, identities, and events by creating stories about the world that selectively contain categories of people, places, and actions associated to emotions. We emphasize some categories; others we overlook (Zerubavel 2015). Our stories act as models of social processes (White 2010:69), conceived in the form of scenarios, that organize our socioemotional reality. They are representations of the way we must think and feel about everyday happenings. Our characterizations are not static, however. They are fluid and are situated in time and space (Lutz and Abu-Lughod 1992). Mass communication is one important level of this cultural creation and dissemination. Newspaper articles, for example, construct and transmit ideas about the world to large populations and thus are important actors in the social processes of culture creation.

Culture is the system of meanings, represented in the form of symbols, by which people understand the world (Geertz 2000). As such, culture permeates all aspect of social life and operates as a driving force in the organization of the social structure. When public policy is debated, for instance, social actors engage in the exchange of broadly circulating cultural meanings and socioemotional classifications that become the narratives guiding the policy processes, and these processes affect social order.

In this paper, I attempt to study culture “in action” by analyzing the narratives on a policy issue debate deployed for broad national and international dissemination in one of the most

influential newspapers in the world. I analyze stories published in the *New York Times* on physician-assisted death (PAD) in 1997, a landmark year for this debate due to a Supreme Court decision on the subject. In recent times, the *New York Times* has been categorized as biased and even accused of overtly promoting this medical practice (Haller and Ralph 2001; Miller 2019). However, an exhaustive analysis measuring the coverage of PAD in mass media in the United States between 1987 and 1996 identifies the *New York Times* as the principal influence in public opinion within the country on this issue. The same study also identified the year 1996 as a year when the issue captured the highest public interest, because of the activism of Jack Kevorkian—a doctor who gained public notoriety for performing euthanasia—and the famous legal cases about the withdrawing and refusal of medical life-support of Karen Quinlan in 1975 and Nancy Cruzan in 1990 (Glick and Hutchinson 1999). My search of the coverage of the *New York Times* on this subject revealed that the coverage in the year 1997 was greater than the coverage in 1996 and also than the coverage during all the subsequent years.

The Quinlan and Cruzan cases are frequently cited as classic examples of the cases that have driven this policy debate in the United States, along with the case of Terry Schiavo in 2005 (Pence 2008).

Using the term “physician-assisted death” has been proposed by the American Psychiatric Association (Anfang et al. 2017) as a way of using neutral language, and it is thus the term I will use in this analysis. PAD may be defined as a subcategory of euthanasia, which is an umbrella term for the death of a patient assisted by a physician. PAD is a form of active euthanasia, in which the patient not only participates in the decision-making process but also self-administers the medication. Ten jurisdictions, nine states and the District of Columbia, have now passed laws legalizing this practice. These laws state that a patient who wishes to make use

of PAD laws is granted the right to request from a physician a prescription for a lethal medication. To qualify for such a right, the person must have been diagnosed as terminally ill and must be intellectually capable of making that choice on their own and also capable of self-administering the medication (Quill and Sussman 2020). These are all provisions that have been modeled after the law that was first passed in Oregon, the first state to make the practice legal in 1994.

Other terms to refer to this practice are “medical aid in dying” and “death with dignity,” the latter being the way in which the practice has been conceptualized in legal bills. Another name used to refer to this practice is “physician-assisted suicide.” This term used to be the mostly commonly used term, but the debate over the last 40 years on this subject has given strong symbolic value to the words employed by the different social actors when speaking about this topic. The cultural attributions to the word “suicide” are seen by advocacy groups in favor of PAD as contrary to their understanding of what people are doing when they request lethal medication to hasten their death in the face of a terminal illness that they foresee will cause them pain and suffering. Detractors of PAD, on the other hand, employ the word “suicide” to signify the risks presented by PAD laws, which are seen as normalizing pathological suicidal ideation. Disability activists opposing PAD underscore the word “suicide” to point to the relationship they see between social stigma, lack of services and support, and the despair that sometimes people with disabilities find themselves in, leading them to suicidal ideation. As a disability rights activist in the movement against PAD writes in a blog, “Suicide is a problem, not a solution for living with a disability” (Tischer 2018).

This article is divided into five sections. The first is a literature review on PAD from a disability studies perspective, one not frequently cited as expert opinion in the debate, and from



the biomedical ethics perspective, from which most expert opinions in the policy debate stem. The second section is a discussion about the intersection between culture, policy, and narrative. In the third section, I describe my method of analysis and how the question “What are people doing with talk of emotion?” (White 2010:67) organizes this narrative analysis of newspaper articles and of the story elements that are under the spotlight (Zerubavel 2015), the story elements that are undermined, and elements that are common to both sides of this public debate. In the fourth section, I conduct the data analysis. I interpret from the articles what are the main formula stories in the discussion on PAD, what are the types of characters and settings, and what are the cognitive, emotional, and moral meanings in these stories. I conclude with a discussion about what the newspaper stories tell us about social understandings, expectations, and emotions and about ways to further this research with the analysis of stories in other levels of social life.

The methodological and theoretical contributions of this narrative analysis are the expansion of efforts to study collective emotions through a cultural, constructionist analysis of a developing policy issue in the United States that has predominantly been approached from either positivist or critical theory perspectives. Other qualitative studies have addressed the ideological framing of PAD in mass communication in an attempt to observe “power in action” by focusing on agenda-setting and the political and economic interests that stir the conversation (Kalwinsky 1998; Glick and Hutchinson 1999), a frequent focus of media studies (Iyengar 1991; Gitlin 1980; Wallack et al. 1993). Yet not enough is known about the underlying cultural meanings that make the plots, or “ideological framings,” in the narratives on PAD even possible in the first place. This study thus focuses on “culture in action” (Swidler 1986) by observing belief systems not as tools to negotiate power but as tools for meaning-making.

## PREVIOUS STUDIES ON PHYSICIAN-ASSISTED DEATH

Most previous research on PAD is from disability studies, bioethics and legal studies, and communications. What most of these studies have in common is that they situate themselves on one side of the debate or the other, with very few exceptions. Most bioethics research has relied on quantitative analysis, with the exception of a few studies that have addressed language (Gerson, Preston, and Bingley 2020; Mitchell 1998). The primary interest in language, however, has come from the disability scholarship.

Disability studies extensively addresses PAD, although this literature has been neglected in the broader public discussion on PAD, resulting in a significant gap in the voices of this debate at the institutional level. In the disability literature, three issues are salient. First is a history of eugenics in the Western world, in which people with disabilities were either put to death or driven to death by abandonment. Second is a lack of mental health services for people with disabilities: PAD may not even be considered if adequate psychological assistance were made available (Basnett, Koperski, and Grumbach 2000, as cited in DeJong and Basnett 2001). Third is a taken-for-granted ableist language (discriminatory representations of people with disabilities) used in the defense of PAD in political, legal, cultural, social, economic, medical, and academic contexts (Altman 2001). Scholars focused on the risk of a “slippery slope” (Kapp 1996) have argued that because of these issues, along with the development of new biotechnological interventions at the end and the beginning of life (Asch 2001; Shakespeare 2006, 2014), it is likely that PAD would be abused, that euthanasia would be legalized, and that both practices would be used indiscriminately, especially endangering the most vulnerable populations (Oliver and Barnes 2012; Ravaud and Stiker 2001). With some exceptions (e.g., Batavia 1997), studies from the disability literature on PAD (mostly referred to in these studies

as “physician-assisted suicide”) have a clear position against the legalization of this policy, a divide in opinion that has also been addressed in the literature (DeJong and Basnett 2001).

In contrast to the relative invisibility of disability scholarship in the policy debate, the literatures from bioethics and legal studies constitute the most common research included in the formal policy debate on PAD to this day and are often studies that accept or support the implementation of PAD. Studies have explored the impact of language (negative connotations of using the word “suicide”) in medical professionals’ perception of PAD and the need to improve training of professionals and services at the end of life (Gerson et al. 2020); the contexts where PAD is most often requested, which are hospices (Campbell and Black 2014); the percentages of US physicians and members of the American Medical Association who oppose and favor PAD (Whitney et al. 2001); and the need to improve caregiving and mental health services to patients who have chosen PAD (Walker and Wong 2018). In other studies, surveyed patients seem to be less concerned about physical or psychological symptoms than they are about losing dignity, control over their bodies, and independence and becoming a burden (Emanuel and Emanuel 1998). Political and legal studies on PAD have addressed moral values such as freedom, autonomy, and dignity in the legal and organizational debate, as well as possible models for the legalization of PAD (Mitchell 1998; Behuniak 2011). Many address complexities in the decision-making of who may or may not be eligible for PAD, given the difficulties of determining what constitutes a valid experience of, for example, hopelessness, which is one of the conditions a patient must report (Hoefler 1997; Strate, Kiska, and Zalman 2001; Ball 2012, 2017; Mitchell 1998) and is often attributed to the artificial prolongation of life, although scholars have argued that the logic of hopelessness predates these sorts of medical advancements (Lavi 2009).

An extensive review of international biomedical ethics literature on PAD attempted to assess the risk for a slippery slope in the implementation of PAD (Rietjens et al. 2012). The authors found the choice of PAD to be related to personal attitudes, family milieus, and communication skills and to be common among people of higher socioeconomic status, whereas women, elderly, unmarried, and less educated individuals—conceptualized as risk populations—were less likely to opt for PAD. The authors interpret these findings as a lack of “clear evidence for a slippery slope” (Rietjens et al. 2012:1286). Studies from the bioethics, legal, and political fields most often have an implicit position in favor of the legalization of this policy, with a few exceptions (Ogilvie and Potts 1994).

Two studies have looked at the issue through a less partisan lens. One, from communications, conducted in 1998, uses framing analysis to explore *New York Times* articles from 1991 to 1996 and focuses on the rhetorical stance of the news (Kalwinsky 1998), in particular, the news outlet’s framing of the issue as one of “individual autonomy.” Another, from political science, looks at the language used in social movements, focusing on two specific interest groups and the value of the concept of “dignity” (Behuniak 2011). My study expands on both of these works, for I conduct a time-situated narrative analysis of the debate in search for broadly circulating cultural narratives. I hope to demonstrate that gaining understanding of the internal structure of cultural narratives in public debate, beyond the agendas of interest groups—a task that entails understanding the symbolic and emotional fields of the narratives—allows us to observe the relationship between culture and policy and ways in which cultural narratives affect our material reality (Loseke 2019; Stone 2002).

## NARRATIVES AND MORALITY IN POLICY DEBATES

### *Narrative as a Theoretical Framework*

This study is situated within the theoretical framing of the narrative paradigm (Fisher 1999). The narrative paradigm is a communication theory positing that humans are storytelling animals who characterize our actions by performing dramatic narratives (MacIntyre 1977). Through the narrative paradigm, researchers view the convictions of our communities, the abstract ideas about the world, the rules, values, and morals that we share and by which we attribute meaning to ordinary experience, as tied to the narratives in our communication. The stories we tell about our ordinary experiences, the stories we hear or read, and the way we interpret these stories are nuanced or guided by cultural structures of social organization. History, biographies, and knowledge are the contexts that inform the meaning-making processes by which we produce stories or interpret their validity, rationality, and morality.

All social ethics involves narratives, and using narrative as a perspective or a paradigm to interpret empirical evidence of social life requires that we understand narrative as a representation intended to classify and make sense of experience (Fisher 1999). In other words, narrative is the tool by which people shape experience in a socially shareable way. Narrative, as an analytical strategy, applies to all forms of human stories (e.g., personal, legal, social, political). As a perspective, it allows us to understand the stories as symbolic actions shaped by a logic of probability and adherence to cultural symbols, intended to generate moral judgments. As Fisher puts it, “Human communication should be viewed as historical as well as situational, as stories competing with other stories constituted by good reasons, as being rational when they satisfy the demands of narrative probability and narrative fidelity, and as inevitably moral inducements” (1999:266).

Literary critics (Todorov 1971; Burke 1969), poststructuralist philosophers (Derrida 1991; Foucault 1972), linguists (Searle 1985; Austin 1962; Van Dijk 1998), communications researchers (Fisher 1999), and sociologists (Loseke 2019) have all recognized the power of storytelling. Stories are present at all levels of social life (Schutz 1970; Loseke 2019; Fisher 1999). Not all narratives or stories and not all storytellers are interpreted in the same way by their audiences, nor do they have the same social impact. Narratives embedded in public policy debates, for instance, are particularly significant because through social policy, narratives shape our material realities. Narratives have internal systems of emotive inclusion and exclusion (Pizzarro 2000:364). In public debates, moral boundaries are defined by cultural and social distinctions among groups of people that motivate emphatic arousal or rejection. In social communication, we construct categories through persuasive messages that define who is included and who is excluded from a group. Political and journalistic rhetoric in public debates repeatedly engage in moral judgments of categories of people by citing moral beliefs to establish people's moral motivation. Public debate narratives reflect and perpetuate moral distinctions that influence audiences. In these narratives, social actors describe human actions and ideas, combined with evaluative categories of moral character, virtues, norms, and emotions (Keen 2015:346), forming a "complex interplay of emotion, cognition, and decision-making" (Schwarz 2000:433).

In sum, the narrative paradigm allows us to explore how the convictions of our communities are tied to the narratives about our ordinary experiences in our communication. Narrative is a representation intended to classify and make sense of experience and to generate moral conclusions. And some narratives are to some degree socially durable maps to understand experience, to morally classify the world; these narratives operate as formula stories, that is,

“scenarios” about human experience that broadly circulate through narratives in given communities.

### *Narrative as a Methodological Tool*

In recent social theory, there has been an increasing interest in the way in which cultural emotions and beliefs are used in political narratives for the purpose of persuasion (Jasper 2011). It is now widely recognized, for example, that studying stories in public debates about policies can help us understand the relationship between policy and culture (Loseke 2019:65; Fischer 2003; Stone 2002) and, more broadly, how intersections between narrative and material life operate in social life.

Symbolic codes are cultural ways of thinking, also referred to as *semiotic codes* and *cultural codes* (Alexander 1992; Swidler 1986; Clark [1997] 2007; Brader 2005; Wood and Rennie 1994; Altheide 2002; Van Dijk 1998). Symbolic codes are “deeply held, inescapable relationships of meaning that define the possibilities of utterance in a cultural universe” (Swidler 1986:282). They are cultural ways of thinking, and emotion codes are cultural ways of feeling (Loseke 2007, 2009). Cultural narratives are the stories about social life and social order that circulate in society and attribute specific connections between symbolic codes and emotion codes, or ways in which emotion should be outwardly expressed, internally experienced, and morally evaluated (Loseke 2009:498).

Some stories operate as templates, by which humans make meaning of regular experience and which circulate in the social world, establishing ethical frameworks. The newspaper articles on PAD, as I will explore in the data analysis, demonstrate the complexity of the ways in which we construct such ethical frameworks through stories. This socially nuanced subject is both a

substantive public policy issue (Behuniak 2011) and a provocative and polarizing debate—operating in different arenas of social life (e.g., academic fields, professional organizations, law)—where one can observe how cultural stories are deployed to motivate action in audiences. Stories in such debates are used and understood in specific social contexts; they make sense of human experience and explain how the world should work (Barker 2003). In this study, I attempt to show how enduring cultural stories in the debate on PAD operate as formula stories (Berger 1997; Chase 2005; Loseke 2012) that offer meaning-making frameworks and practical guidelines regarding social order.

The construction of narratives precedes the creation of norms or prescriptive systems of ideas (Elias [1969] 1994). In social networks, there are repeated associations of socially circulating codes and symbols and specific emotions (Loseke 2007, 2012), and the construction of stories includes building identities. Through language, we build figurations of social networks: “narrative identities are constituted by a person’s temporally and spatially variable place in culturally constructed stories composed of (breakable) rules, (variable) practices, binding (and unbinding) institutions, and the multiple plots of family, nation, or economic life” (Somers 1994:625). Stories of individual, family, and national identity have collective representations (Durkheim 1961) and contain specific plots or formula stories (Berger 1997; Chase 2005; Loseke 2012) that cite socially circulating associations between the symbolic and emotion codes. The identities of characters in stories work as “moral inducements” (Fisher 1984:2).

In today’s world, building narratives for persuasion is complicated by the fact that expectations and evaluations of identity categories are very diverse and change frequently (Loseke 2019:30). Yet researchers who provide knowledge to policy makers are expected to shed light on “what works,” as opposed to offering complicated qualifications (Whitehurst 2003),



because policy making is a process of simplification in search of standardized solutions to complex social problems (Stone 2002). Research on cultural meaning-making can trouble policy-making processes because it accomplishes the opposite of the goal of “accommodat[ing] the complexities of social life” into simplified analysis (Donmoyer 2012:799). Instead, such studies can highlight the complexities in a given subject and expand the areas of debate in a policy-making process.

Scholars of culture, narrative, and policy agree that individuals in civil society “live in a state of chronic antagonism, driven by opposing interests” (Eagleton 2000:7; Alexander 1992; Stone 2002). The policy arena may be understood as a realm where material interests and power articulate cultural ideas into an “ideology,” a concept that can be defined as “a highly articulated, self-conscious belief and ritual system, aspiring to offer a unified answer to problems of social action” (Swidler 1986:279). Under such a perspective, civil society is a social institution whose opposing interests are to be resolved by the state through policy making (Eagleton 2000). In this study, I adopt an alternative understanding of civil society, seeing it as part of culture, a sphere where antagonism and cohesion are constructed through symbolic codes, shared beliefs about the world, with subjective moralities operating in the sphere of symbolism. Symbolic codes can be the glue for social cohesion, for the construction of groups even within heterogeneous constituencies who vote or become part of social movements based on unifying symbolic understandings of very diverse human experiences. However, symbolic codes are merely shared meanings, and their “explicit demands [to action appear] in a contested cultural arena” (Swidler 1986:279).

Alexander (1992) argues that all sociological studies of civil society should include an analysis of this symbolic sphere, which operates in binary symbolic sets, a reflection of how we

in the Western world tend to think and categorize. Across social groups, he argues, there are two civic sets, civic virtue and civic vice, and it is through symbolic codes that the conditions of purity (virtue) and impurity (vice) are established (Alexander 1992:300).

What changes across groups is not the presence of this binary opposition, even though human experience is a continuum. What changes across groups are the social actors to whom members of civil society attribute the organizing symbolic codes of purity and impurity. The internal logic of the symbolic code is used to classify right and wrong through expressions, sometimes in the form of analogies and metaphors alluding to specific emotions. “We experience [the world] as discrete chunks: ‘strangers’ and ‘acquaintances,’ ‘fiction’ and ‘nonfiction,’ ‘business’ and ‘pleasure,’ ‘normal’ and ‘perverse’” (Zerubavel 1996:421). So each symbolic code, or “cultural way of thinking,” is classified by an emotion code, or “cultural way of feeling” (Loseke 2009): we like or dislike a symbolic code, we fear it or trust it, and so on, and at the macro-level of society these symbolic interplays of symbolic and emotion codes generate a situated emotion culture (Stearns and Stearns 1985; Gordon 1990; Moïsi 2010).

By examining the cognitive, emotional, and moral meanings in the competing stories in a public policy debate such as PAD, as shared in mass communication, we can gain understanding on the work that those stories do in social action and structural changes. Observing the work done by stories, especially the types of formulaic stories that circulate at the macro level of society and that pertain to a public policy issue, is also a way exploring how culture affects the material lives of people.

## METHODS

### *Site*

I analyze news reports because they offer stories that are meant to provide new information (Van Dijk 2013) and to draw readers in with dramatic elements (Barkin 1984) to keep us engaged and affect the construction of our collective identity (Schlesinger 1991; Van Dijk 2013). These stories are presented as truth, regardless of any actual relationship they might have to “truth” as empirically/scientifically measured. News stories focus on specific elements to generate “story lines” that make sense and that are not disrupted by inconsistencies, even when the story lines of events may have inconsistencies (Jamieson and Waldman 2002). I thus observe which story elements are under the spotlight (Zerubavel 2015), which are invisible, and which are common to both sides of this public debate.

The context for these stories is the year 1997, when the United States Supreme Court declared that there was no fundamental right in the Constitution to commit suicide but that states could decide to legalize physician-assisted death (Mariner 1997). Two cases that had been brought to the Supreme Court sparked the interest of the media: *Washington v. Glucksberg* (Washington State) and *Vacco v. Quill* (New York State). The *New York Times* printed more than 70 articles touching the subject of PAD that year, including opinion articles, editorials, and journalistic chronicles. The court cases were the reason for the printed press’s attention on PAD that year, and the case arguments heard on January 8 were the framework for the narratives in the newspaper articles.

### *Data Selection and Classification*

This article is part of a larger research project whose objective is to study connections of cultural meanings across levels of social life: mass communication, civil society, and policy regulation in the context of today's technologically advanced medicine. The data in this part of the broader research project are 44 newspaper articles published in the *New York Times* during the year 1997. Following the theoretical precepts of the narrative paradigm, the method I apply (Glesne 2016) is a narrative analysis of the stories in this news coverage of PAD. The choice of the dates for the journalistic coverage of PAD is directly related to the court cases of *Vacco v. Quill* and *Washington v. Glucksberg*, both of which took place in 1997. To select the outlet, I first searched through the Nexis Uni data repository for newspaper articles using the three most common terms by which this medical practice is referred to: "physician-assisted suicide," "physician-assisted death," and "aid in dying." I chose the articles from the *New York Times* because it had the largest number of articles and because of its national and international prestige: a record number of Pulitzer Prizes and its recognition as a newspaper of record. I then selected the 94 *New York Times* articles found through the search term "physician-assisted suicide" (PAS). Out of the 94 articles drawn from the Nexis Uni search—a search I corroborated with a search in the *New York Times*' online database—42 articles significantly addressed the subject; the other 52 articles were discarded because either PAS was mentioned only in passing or the articles were letters to the editor and therefore not reflecting the newspaper's construction of meaning. Together, the 42 articles add up to roughly 20,000 words.

To do the analysis, I saved the articles as PDFs and entered them into the qualitative data analysis program Maxqda, which aided in classifying the data.

In the analysis, I study the logic in broadly circulating stories behind the policy-making process of PAD, to understand the processes of polarization in the debate. I examine how articles in the *New York Times* constructed the meaning of PAD, and I look at the way opposing groups are internally and externally categorized through the articles' stories. In these stories, I look for the *symbolic identifications* within the internal structure of their narratives (Alexander 1992:300). I demonstrate ways in which the stories build their coherence and explain views about human experience within schemes of social values and claims about social problems (Gubrium and Holstein 1997; Alasuutari 1997; Baddeley and Singer 2007).

I explore the characters built into the narratives and identify how they are situated in social contexts (McAdams 1996). In these newspaper articles, social actors are described in interaction with one another in personal, institutional, and organizational contexts, from family homes to hospitals and courts of law, but also within webs of meanings and broadly shared morals and values. I search for the predominant formula stories, including common types of characters and common types of settings where the characters interact, and observe the cognitive, emotional, and moral dimensions of those character types (Gubrium and Holstein 1998; Loseke 2019). I focus on the scenarios in which talk of emotion is used to characterize people and situations. The guiding question of my analysis is thus: What are the most prevalent cultural beliefs in the narratives, and in what ways are they appealing to emotions? Or in the words of White, "What are people doing with emotion talk?" (2010:68).

## DATA ANALYSIS

The 42 *New York Times* articles contain cultural beliefs and emotional models regarding the legalization of PAD that broadly circulated in the US in the late 1990s. Through their internal

emotional, cognitive, and moral meanings, these stories offer their audiences templates for the understanding and meaning-making of the possible human experiences in the complex scenarios of the legalization of PAD.

Thus, in this analysis, I interrogate the data with practical questions in an attempt to understand the internal meaning-making in the narratives to explore the underlying question, “What are people doing with emotion talk?” (White 2010:68). I conceptualize what White calls “emotion talk” as a form of “speech act” (Austin 1962) that is performed by connecting ideas and emotions through words. Speech acts are a concept developed by language philosophers to denote the way in which humans use language not only to communicate information but also to generate an effect on others. I wish to demonstrate that through the study of public narratives and the cognitive, emotional, and moral dimensions of the stories (Loseke 2019), we can observe important dynamics in the relationship between culture and collective emotions, approaching an understanding of “what is the role of emotions in mediating social action” (White 2010:69). Hence, my first empirical question is: *What are the predominant formula stories in these narratives?* Next, I ask: *Who are the common types of characters, and what are common types of settings in the stories?* Finally, I ask: *What are the interwoven threads of cognitive, emotional, and moral meanings?* (Loseke 2019).

### *Predominant Formula Stories and Their Plots*

The narratives in the discussion of PAD in the *New York Times* articles make claims about social problems and construct specific character identities and scenarios that these characters may experience. From these elements emerge two predominant formula stories: a story about a *good death*, central to the movement for the legalization of PAD, and a contending story of a *slippery*

*slope*, central to the movement opposing the legalization of PAD. In these stories, symbolic codes establish sets of shared beliefs about the world. They operate as the symbolic glue for social cohesion, constructing groups even within heterogeneous constituencies. They unify symbolic understandings of diverse human experiences. They also generate antagonism with a contending set of shared beliefs, for each set has subjective moralities operating in the spheres of cognitive and emotional symbolism. While any story can be read in multiple ways, here I focus on how the *good death* and the *slippery slope* can be read as central formulas of meaning organizing the symbolic and emotion codes employed in each side of this debate. Here are examples of explicit use of the terms *good death* and *slippery slope* that show their centrality in the narratives:

Courtesy of the assisted-suicide debate, the concept of a good death has now emerged, though many experts reject the phrase as simplistic. Dr. Ira Byock, president of the Academy of Hospice and Palliative Medicine, prefers “dying well.” Dr. Timothy Keay, an end-of-life care expert at the University of Maryland, says “the least worst death.” (Art.28.OPINION.06.29)

Permitting assisted suicide would put us on a moral “slippery slope.” Although in itself assisted suicide might be acceptable, it would lead inexorably to involuntary euthanasia. It is impossible to avoid slippery slopes in medicine. (Art.22.SCIENCE. 06.24)

At the base of the good death narrative is the importance of having independence, dignity, and privacy in relation to one’s body. Death and birth are personal decisions of the

rational actor. For the narrative of a good death to exist, there must be a narrative of the bad death, a sort of death that has to be avoided because it is horrific. The narrative also contains a subplot about a social problem related to dying with excessive and unnecessary biotechnological intervention and to the existence of an underground practice of PAD already in place. The moral argument of this narrative is that it is cruel and criminal to let people die in ways that involve pain and loss of bodily functions. In this story, the legal actors preventing the policy are the villains, and the doctors who have to help patients attain a good death without protection from the law are either the victims or heroes, although there is a recognition that there can be exceptional cases of unscrupulous doctors. In this story, patients are tangential to the debate. The primary setting in this narrative is the home, where the good death should happen, without pain, with full bodily self-control, in the proximity of loved ones, and without enormous financial debts. In the good death narrative, doctors are often quoted relating their experiences with patients who have had either good or bad deaths, and they often complain about a legal system that does not let them help their patients as much as they would like to.

At the base of the slippery slope narrative is a fear of abuse of PAD, as well as a fear of its acceptance leading to the legalization of involuntary euthanasia. As in the good death story, here there are references to social problems, but here the problems are of a different sort: discriminatory practices in the medical field and a discriminatory social structure that would lead to abuses of PAD, as well as practice that is illegally already taking place and goes unpunished. Families will convince their elders not to “over live”; people with disabilities will be killed without control, by families or by physicians; and patients will choose PAD because of fear of financial hardship or because of untreated depression. PAD supporters’ claim for freedom is understood as naiveté. The idea that allowing doctors to prescribe lethal medication to patients



who have been diagnosed as terminally ill with only six months to live is seen as ignorance about what really happens on the ground. Depressed individuals may not be sufficiently encouraged to seek psychological help, and psychological help is scarce or simply unavailable to the most vulnerable populations. In this story, unscrupulous, sometimes criminal, and at best naive doctors are the villains, and vulnerable patients are the victims; other primary characters are uncaring family members. There is not a predominant physical setting in this narrative; the settings are the abstract ideas of the medical field and the socio-legal structure. In the slippery slope narrative, a variety of authoritative voices, including politicians, doctors, and intellectuals, characterize the medical system as faulty and potentially dangerous for vulnerable populations.

However, these two stories are not completely binary. For instance, in the good death story, there is an internal differentiation between those who defend the practice for what they characterize as the “right” reasons and with the “proper” procedures, that is, for patients’ benefit and with accountability, and those whose moral motivations and practice are characterized as dubious, that is, for self-aggrandizement and without accountability. In several of these articles, this opposition is characterized through two specific opposing figures: Dr. Timothy Quill, plaintiff in the case *Vacco v. Quill*, and Dr. Jack Kevorkian, a well-known advocate and implementer of PAD.

More Marcus Welby than Jack Kevorkian, Dr. Timothy E. Quill treats bronchitis and acne, high blood pressure and diabetes, depression, and sprained ankles. He cares for several generations of the same family and makes house calls. (Art.1.NY.01.02)

Proponents of the right to die describe Dr. Kevorkian, a retired pathologist who had no previous experience with dying patients, as a rogue; Dr. Quill has said that Dr. Kevorkian is “out of control.” If there were clear guidelines for the practice of assisted suicide, proponents reason, Dr. Kevorkian could be held accountable for failing to follow them. (Art.18.US.06.11)

“[Dr. Quill] is a good representative of what ought to happen, because death is not his subspecialty but an integrated part of his practice.” ... “He treats someone as a whole person, not an anticipatory corpse,” as opposed to Dr. Kevorkian and others “who have a stake in finding clients and justifying their own existence.” (Art.1.NY.01.02)

In the first two quotes, descriptions of the characters are presented as statements of fact, yet they have implicit emotional and moral appeals. Dr. Quill “cares for several generations of the same family” and is thus a caring doctor, while Dr. Kevorkian does not follow proper procedures and is an irresponsible, therefore possibly uncaring, doctor. The third quote has more direct moral judgments of each character, with Dr. Quill representing benevolence and Dr. Kevorkian representing selfishness.

### *Types of Characters and Settings*

#### CHARACTERS

The characterizations above are common ways in which stories created in the context of public debate reduce the complexities of real-life people into what Loseke (2019) calls “formula stock

characters.” This way, through the evaluation of individual identities, the narratives persuade audiences to take these stories about individuals as stories about types of characters.

The *New York Times* articles about PAD contain three fundamental character types: doctors, political decision-makers (including judges), and, to a lesser extent, patients. Other types of characters, such as professional or family caregivers, are at the margin of the stories. With the exception of one article, patients in the good death story are only mentioned through their relationship with doctors, and they serve only as references for the doctors’ character. In the following quote, the individual identity of Sigmund Freud is typified as the educated patient who would request PAD. This is precisely the type of patient that current annual reports from the Oregon health department on the use of PAD state are the majority of users (Oregon State 2019). However, even this historical figure is described through his relationship with his doctor. The story is as much about the doctor who helped Freud not feel pain in death as about Freud’s experience.

In April 1923 Sigmund Freud was found to have cancer. ... Early on he told a new doctor, Max Schur: “Promise me one thing: that when the time comes, you won’t let me suffer unnecessarily.” They shook hands. On Sept. 21, 1939, Freud told Dr. Schur: “My dear Schur, you certainly remember our first talk. You promised then not to forsake me when my time comes. Now it’s nothing but torture and makes no sense anymore.” Dr. Schur wrote later: “I gave him a hypodermic of two centigrams of morphine. ... The expression of pain and suffering was gone. I repeated this dose after about 12 hours. Freud was obviously so close to the end of his reserves that he lapsed into a coma and did not wake up again.” (Art.7.OPINION.01.10)

In this quote, we see how the doctor is the hero, the one who allows Freud a good death, even though Freud's voice is also present in the quote expressing his desire for a good death. The more common references to patients, however, contain mostly the perspective of the doctor. Here is one example where the doctor is the protagonist, and the patient is referenced to characterize the heroic actions of the doctor:

“These few bad deaths must be considered a medical emergency,” [Dr. Quill] said.

“People sometimes end up in very bad situations at the end of life, and you have to be creative, bold, in the way you help them. You hope it doesn't involve anything active.

But you solve what has to be solved.” (Art.1-NY.01.02)

In the slippery slope story, by contrast, doctors are the villains, either unscrupulous or naive, characterized through the broadly shared symbolic codes of “the cost-conscious doctor taking advantage of the vulnerable” and “the doctor who is oblivious to the reality of the system and the patients”:

The poor, disabled, and elderly might be coerced to request [assisted suicide]. ... Cost-conscious doctors might pressure vulnerable patients to request suicide.

(Art.22.SCIENCE. 06.24)

Daniel Callahan ... called Dr. Quill a nice fellow, cautious and moderate. But he said Dr. Quill was naive to conclude that legal assisted suicide would not leave powerless patients vulnerable. (Art.1-NY.01.02)

In the slippery slope story, patients are mentioned infrequently. In the few places where patients are mentioned, such as in the following quotes, they are pure victims without agency, forced into choosing PAD because of either family coercion or depression. In these examples, uncaring family members are also depicted—“a mean wife” and “opportunistic kin”:

A wife who no longer wished to care for her sick husband gave him a choice between euthanasia and admission to a home for the chronically ill. The man, afraid of being left to the mercy of strangers in an unfamiliar place, chose to be killed; the doctor, although aware of the coercion, ended the man’s life. A healthy 50-year-old woman, who lost her son recently to cancer, became depressed, refused treatment for her depression, and said she would accept help only in dying, was assisted in suicide by her psychiatrist within four months of her son’s death. (Art.21-SCIENCE.06.24)

One can only imagine the deathbed turmoil of kin in conflict. Money, morphine, guilt, control, and convenience are common subplots in the drama surrounding a terminal patient. (Art.9.NY.01.12)

Her sister, Simi Linton, who teaches psychology in Hunter’s Division of Education, is an expert in disability studies and is disabled herself. Legal doctor-assisted suicide, she said,

would be the “slippery slope” down which a lot of people in wheelchairs would be rolled to death. (Art.22.SCIENCE.06.24)

In the good death narrative, another type of character that is constructed is a villain who will deprive individuals of the right to a good death. These villains are the political detractors of the policy. In the following quote, a “demagogue” preventing Measure 16—which established the Death with Dignity Act in Oregon (Cohen 1995)—demonizes the idea of PAD:

The Legislature, which has become more conservative since 1994, voted to send Measure 16 back to the voters rather than tinkering with its flaws. In the floor debate, one state senator brandished a plastic bag as a reminder of the suffocation sometimes needed to bring death to a terminally ill patient when pills are not immediately enough.  
(Art.20.US.06.17)

## SETTINGS

The simplification of settings is another way to reduce the complexities of real life to manageable single images. In the good death narrative, for instance, home is the symbolic setting for a good death, the setting that modern medicine has displaced. It is a place that is not characterized by location, structural limitations, or physical attributes but by emotional and moral value. In the following three examples, there are implicit and explicit moral evaluations of the proper setting to die:

At the turn of the century, virtually all Americans died at home. Most dying people lingered a few weeks or months, almost always nursed by female family members. (Art.13.NY.03.23)

[The hospital] is not a good place to die. A large proportion of people die in pain. The hospital wards are busy; the nurses and doctors are busy. They're surrounded by people they don't know. They're not with their loved ones. (Art.13-NY.03.23)

Mrs. Randall had been in failing health for years. She wanted no more treatment. She asked to go home and die in her own bed. (Art.1.NY.01.02)

In the first quote, which presents factual information, home is characterized by the presence of dedicated family care, specifically female, establishing a historical background of taken-for-granted social roles. In the second quote, however, which comes from the same article, there is the direct contrast between home and the hospital: the hospital is a place where love is absent. In the third quote, there is an emotional attachment to place and its objects, a sense of belonging that is marked by the ownership of objects and the agency of choosing those objects and place for the moment of death. Thus, in the good death narrative, home is a symbol of an idealized setting where excessive modern interventions can be avoided in order to attain a good death.

In the slippery slope story, however, there is not a physical setting per se. The slippery slope story is about preventing the legalization of an action, so the primary settings in this story are abstract: the medical institution and the socio-legal structure as a whole:

But what troubles many of those who oppose assisted suicide ... is ... to put the nation on a slippery slope, without first changing the health care system and improving access to hospice care. (Art.1.NY.01.02)

“There’s fear of any kind of institutionalization of assisted suicide, that people might feel that somehow it becomes a duty to die,” said Mr. Smith. (Art.30-US.07.03)

Thus, in the slippery slope story, the institution of medicine is a symbol of an impersonal, negative space where there is potential for extreme danger, in contrast to the good death narrative, in which the familiar physical space of the home is a symbolic safe haven.

In sum, the stories of the good death and the slippery slope have some of the same symbolic characters (e.g., doctors, patients) but with differently attributed moral codes of villains, heroes, and victims. Moreover, the stories have different types of elements in them; for instance, the slippery slope story does not have a concrete setting, perhaps because there are no concrete domestic scenes in this story, no anecdotes. The slippery slope story is more of a discussion about hypothetical scenarios and the moral attributes of medical professionals. The good death story does have concrete examples, scenes of action, and outcomes.

### *Cognitive, Emotional, and Moral Meanings*

In this section, I continue to explore the characters and settings described in the previous section but now in terms of how they move through the plot of the good death and slippery slope narratives. Here, I focus on the cognitive meanings (ways in which people think), emotional



meanings (ways in which people feel), and moral meanings (people's judgments about right and wrong) described in the narratives.

There are two central cognitive codes common to both narratives: (a) the existence of an ongoing underground practice of assisted suicide already taking place; (b) the public discussion on PAD being a catalyzer for the opening of the discussion regarding improvements for end-of-life care and palliative care.

The symbolic representation of PAD as an existing and broadly unreported medical practice is repeated numerous times throughout the articles and in both narratives:

Both sides in the debate over assisted suicide say the practice is likely to continue underground in the way doctors say it has been done quietly for years. (Art.26.US.06.27)

In the good death narrative, there are descriptions of how doctors already practice PAD outside of the law because they wish to "help" their patients. In the good death narrative, "help" is defined as providing a good death; the moral judgment of this practice is positive:

But so many doctors already help their terminally ill patients, in a wink at the law, that Oregon's act would simply legalize an existing practice, supporters of assisted suicide say. They point to a survey of doctors in Washington State ... [that] found that 25 percent of doctors had been asked to help end a life, and 25 percent of the patients who had made such a request were given prescriptions to end their lives. (Art.38.US.10.26)

The same representation of PAD as already being broadly practiced is present in the slippery slope story. However, in the slippery slope narrative, “help” is “conceded,” as a crime would be, and therefore the moral judgment on this action is negative. Descriptions of how doctors criminally practice PAD with impunity are the contents of these stories:

While nearly all 50 states have statutes that in effect make physician-assisted suicide a crime, and although many doctors concede in surveys that they have helped dying patients to end their lives despite these prohibitions, the act goes virtually unreported, uninvestigated, unprosecuted, unpunished. (Art.25.US.06.27)

The two narratives appeal to different emotions and moral judgments in audiences. In the good death narrative, the use of the verb “help” in reference to doctors who are already performing PAD constitutes an emotional and moral appeal to formalize the practice. The slippery slope narrative also cites “facts” about the practice being in place but condemns it through using the terminology of crime.

The public discussion on PAD is frequently conceptualized as a catalyzer for the necessary discussion about the quality of palliative and end-of-life care, regardless of one’s moral judgment about the issue. In the slippery slope story, this catalyzer for discussion may also serve as the means to end the need for PAD:

“My hope is that this discussion and the higher level of consciousness about what constitutes high-quality, end-of-life care will actually reduce the underground practice of assisted suicide,” said Dr. Diane E. Meier. (Art.26.US.06.27)

In the good death story, PAD as a catalyzer for discussion—even when facilitated by bad doctors—has opened the opportunity for doctors to gain understanding about the end of life and the importance of improved care.

The debate over physician-assisted suicide [that] Dr. Kevorkian has raised is helping to improve palliative care and change attitudes among doctors. (Art.41.NY.11.16)

“The people in favor of assisted suicide are the biggest proponents of hospice and pain control,” he added. “The difference is that we are realists. We know it doesn’t always answer every patient’s needs, and there are still patients who are suffering because of it and who don’t want what it has to offer.” (Art.26.US.06.27)

Part of the discussion about the improvement of care is also the symbolic code of the management of pain, associated to the emotion code of guilt in the following example:

“We don’t put our animals through the pain that we allow other humans to suffer.”  
(Art.32. NY.07.13)

As mentioned earlier, an important symbolic code in this conversation, particularly in the good death narrative, is the setting where death happens. In the good death narrative, the place where the end of life should occur is discussed in relation to the type of care received by the

patient. Home is where one should die, cared for by loved ones. Hospitals are for saving lives, but medical professionals in hospitals are not equipped to emotionally care for patients:

The family never debated whether to put Mr. Clause into a nursing home. ... “I couldn’t imagine walking out and leaving him,” Mrs. Clause said of nursing home care. “It would definitely kill me.” At home someone is there, always, to meticulously bathe and soothe Mr. Clause and to catch and wonder over his every mouthed word. “We really listen,” Mrs. Rizzo said. “We don’t want to miss a minute. He does, too.” (Art.13.NY.03.23)

In this quote, the symbolic code of home as the proper setting for death is associated with the emotion codes of love and care through the descriptions of the family interaction. So cognitively, death requires special care given in a physical setting where such care is possible: the home of the person. Emotionally and morally, death is “traditionally” a family matter, with tradition here having a positive evaluation. However, in relation not to the setting of home but to the application of the law, the good death narrative also shows a negative evaluation of the idea of tradition:

Petitioners stress the long tradition of prohibition against suicide, including penal laws dating to the founding of this country. But such laws derive from a time when death was rarely preceded by long periods of physiologically degenerative suffering. ... The cases before the Court, however, involve degenerative death, a creature of modern medicine; they should therefore be decided on a historically clean slate. (Art.2.WEEK.01.05)

As stated earlier, the slippery slope narrative does not make reference to a physical setting. Interestingly, the end of life of people who do not die near family is not discussed by either side. However, today, after all the years of PAD implementation, there is evidence that in the US the majority of people who request to hasten their death through PAD do so in hospices (Campbell and Black 2014).

There are three topics that would potentially be important topics for discussion on both sides of the debate but that seem largely ignored in these articles, mentioned only one time each. The first topic is the conceptualization of PAD as a new medicalized way of dying:

When Oregon enacted the nation's first law permitting doctors to help their terminally ill patients commit suicide, the state was expected to become a national laboratory for a new way of dying. (Art.17-US.06.10)

The second topic is the effectiveness of the lethal drugs and the diagnostic difficulties that complicate eligibility for PAD:

Opponents say new information has emerged, like findings in the Netherlands that 25 percent of patients given lethal doses of oral medication do not die within three hours and a survey showing that 50 percent of Oregon doctors are not confident they can predict when a patient has just six months to live, which is the law's definition of terminally ill. (Art.17-US.06.10)

The third topic is the emotions of surviving family members:

“It was a very selfish act,” his wife, Carla Fine, said recently in the Chelsea apartment they bought together in 1981. “People talk about the boldness, the audacity of suicide, but I see it as coping out. It’s done out of fear and anxiety, not strength. The brave people are those who mop up the blood with Clorox, who clean the brains off the wall, who comfort the survivors.” (Art.14-NY.03.30)

These neglected three issues, however, have social consequences. Additional studies could determine if they are further addressed at other levels of public discussion.

The two Supreme Court cases—*Washington v. Glucksberg* and *Vacco v. Quill*—are at the center of most of the stories in these newspaper articles. They are part of the shared cognition regarding PAD. Thus, the topic’s complexity is described in the stories in relation to arguments used in these cases. In the articles, the debate is described as taking place in an overall emotional atmosphere:

On Wednesday, the Justices will hear two hours of argument in the cases, which have brought a fascinating array of briefs expressing passionately held views about issues of life and death. ... With a fervor rarely seen at the Court, these briefs explore questions about medical practice, the meaning of death and the relationship of the individual to the state. (Art.2.WEEK.01.05)

We find ourselves trying to make sense of an issue that, by its very nature, deals with the most irrational currents of the human mind. But how can we realistically expect

objectivity, from ourselves or lawmakers or the Supreme Court, on an issue so fraught with psychological turmoil? The inherent irrationality that the subject of death arouses in people has been largely overlooked in the debate on assisted suicide.

(Art.10.OPINION.01.13)

The analysis of the stories in this debate makes it clear that at the center of the public discussion on PAD, there is an entanglement of emotional, practical, moral, and ethical issues related to the medical profession, civil rights, and the meanings of life and death. The articles show this complexity by underlining that this subject has no simple answers, as we see in this article segment:

Despite the black and white legal arguments heard by the Supreme Court, this is not primarily a legal or even a medical issue. Rather ... “It’s basically a spiritual, emotional, psychological issue that involves redemption and courage and dignity.”

(Art.31.WEEK.07.08)

The construction of the good death narrative uses the word “dignity” as a call for an emotional response to the practical matter of losing full control of one’s body. Here is one example where the term is used to characterize patients in need of PAD as deserving recognition and another example where dignity is associated with the symbol of home. Both examples are calls for lawmakers’ compassion through moral and emotional allegations:

This [editorial] page has argued that terminally ill, mentally competent adults nearing death should have the option of dying with dignity, in full control of their bodies and final moments. ... We hope the Court will see clearly the profoundly important issue of personal liberty that lies at the controversy's core. A wise decision would recognize both the rights of suffering terminally ill patients and the duty of states to craft safeguards to prevent abuse. (Art.3.EDITORIAL.01.06)

Proponents of the law argue that people have a fundamental right to die with dignity and to have the option of obtaining the means to hasten their death if end-of-life suffering becomes intolerable. Patients should be able to die on their own terms in their own homes, the proponents say. (Art.20.US.06.17)

In contrast, the perspective of the slippery slope narrative is that PAD represents a grave risk in a society that is not morally and emotionally prepared to change social dynamics of power and inequality. Vulnerable people could be coerced to request PAD or become victims of their own depression, as we saw in earlier quotations. Those who are often given less social value in society would be at great risk:

Many persons with disabilities exist in a state of “virtual terminality” because the frailty of their physical condition and the specter of death are so intimately woven together. In turn, a constitutional decision asserting that their right to live is constitutionally disposable makes them “virtual aliens” because their most fundamental right—the protection of life—would hang only by the single thread of their own resolve to keep it.



They will be left far less secure against both internal and external pressures to give away this right to the unjust advantage of others. (Art.2.WEEK.01.05)

The concern observed by disability scholars about the language-discrimination aspect of arguments in favor of PAD is not directly addressed in the articles within the slippery slope narrative. In the good death narrative, however, there were a few examples of such language, such as this one, in which physical experiences that a person with disabilities might have on a regular basis are conceptualized as leading to despair and distress to the point of justifying death:

A competent, terminally ill adult has a constitutionally cognizable liberty interest in avoiding the kind of suffering experienced by the plaintiffs in this case. That liberty interest encompasses an interest not only in avoiding severe physical pain, but also the despair and distress that comes from physical deterioration and the inability to control basic bodily or mental functions in the terminal stage of an illness. (Art.2-WEEK.01.05)

## DISCUSSION

In each side of this debate, the characters of the contending story are symbols of vice and impurity, and the internal characters are associated with symbols of virtue and purity (Alexander 1992). The binarism of the stories is not exact, however; there is a subset of internal characters in the good death narrative that are deemed as less ethical and thus separated within this narrative. From the good death perspective, to die well is to avoid extreme and unnecessary medical intervention, suffering, and hardship and to die with control of oneself, with dignity, a concept whose nuances are open for interpretation. In this perspective, PAD should be a matter of

personal liberty, a legal choice, and not allowing the legalization of PAD—which is described as already happening on the ground—would be morally wrong, almost criminal. In the story of the good death, the United States is a democratic country where people have choices and autonomy and where nobody deserves to suffer in any way if it can be avoided. Families should be able to preserve harmony and keep every member healthy, happy, and independent. People would recover the historically lost option of dying at home with the aid of a caring physician. Physicians could have the freedom to help. It could be argued that the good death, as it is articulated in these narratives, operates as a substory of the America Dream, which embraces a vision of the world with cultural codes such as individualism, fair play, meritocracy, and family attachment and responsibility (Loseke 2019:23).

For the slippery slope perspective, to allow PAD is to put citizens at great risk. The general scene is one of deep material inequalities in the US, including inequalities at all levels of social and institutional life, and PAD represents a threat of abuses of power. The slippery slope narrative presents a story of vulnerable populations left without sufficient safeguards in the hands of unscrupulous doctors, unloving and uncaring family members, and discriminatory social structures. In 1997, the details of which vulnerabilities in the population mattered the most were being defined. By 2019, however, Oregon's Death with Dignity Act report asserted concern over specific vulnerabilities by stating, in its summary of patients' characteristics, that the most vulnerable populations are not the ones who are using PAD, defining the users of PAD as white, educated-class individuals (the underscored vulnerable population therefore being nonwhite and uneducated individuals). However, people with disabilities are not mentioned in this summary (Oregon State 2019:6).

In sum, the good death narrative contains the claim that modern death is intervened by excessive medical technology, which leads to unnecessary suffering of the patient. However, a significant characteristic of these newspaper articles' construction of this narrative is that patients themselves do not appear to be the primary characters; doctors are, and the experiences, needs, emotions, and perceptions of patients are constructed by others.

The slippery slope narrative contains the claim that social inequality and discriminatory values in the medical field and in the social structure would lead to abuses of PAD. Neither one of the narratives responds to the claims of the other. The good death narrative presents PAD as a symbolic code of help, appealing to empathy. The slippery slope narrative presents PAD as a symbolic code of inevitable threat, appealing to fear.

There are common views, however. Both sides agree that PAD has opened a necessary conversation about the way people die in the United States. Another common view is that thanks to this conversation, more is known today about the need for improvements within the end-of-life care services.

This paper is an examination of the ways of thinking and feeling that were broadly shared through the stories told in the press about this critical policy-making process, and as such, it contributes to the understanding of public policy in general and more specifically to the understanding of end-of-life medical interventions. The paper informs about potentially underlying or taken-for-granted values, emotions, and issues operating in the policy-making processes, and its findings may aid policy makers and other social actors, such as those who are directly regulated, serviced, protected, or affected by the new policy, for it points to unattended opportunities for discussion. The PAD debate, as represented in the *New York Times* articles, speaks less to cognition than to emotions and moral evaluations: statistical or scientific

information is hardly addressed, and types of people, circumstances, and moral assessments are the predominant themes.

Policy-making processes are influenced by our collective ideas about the world (Stone 2002; Fischer 2003); therefore, empirical analysis about the views of stakeholders in the matter can inform the policy-making process. In the case of PAD, there is a great diversity of actively interested parties. This issue is pressing for the disability community, inside which the concerns over PAD are twofold and practical in nature. Disability activists denounce, on the one hand, the discriminatory language against people with disabilities in discussions about PAD, in which disability is conceptualized as being worse than death. On the other hand, they fear that, in such a cultural context of discrimination, the law will be expanded well beyond cases of terminal illness and that it will ultimately serve as a eugenics device against people with disabilities. The issue is also important to medical associations because they fear PAD will generate a dangerous shift in the culture of the medical profession, which has traditionally focused on saving lives. Religious organizations also have a vested interest in this topic because it is a battleground for the defense of the “sanctity of life,” a concept that has traditionally been known as the principal argument against PAD in public debates on the subject (Ball 2017; Lavi 2009). It is also pressing for doctors who are held legally or socially liable for assisting patients who seek PAD, for family members who support this decision, and for those who do not. PAD is also an issue of interest to politicians and social movements, as well as to the media, writers, and filmmakers.

Working on processes of policy making that are still under development is a unique opportunity for qualitative sociologists. Under such circumstances, researchers can witness the situated collective consciousness (Durkheim [1893] 2014), the politics of emotional discourses (Lutz and Abu-Lughod 1992), and the shared cultural ideas guiding the conceptualization of laws

and regulations. In other words, interpretive analysis can improve the knowledge we have about abstract factors such as emotions and subjective moralities operating in the background of a public policy discussion at the national level (Berger and Luckmann 1967).

Narrative analysis provides the necessary tools to observe meaning-making processes built on storytelling, a predominant tool of argumentation in public life. This method allowed me to treat civil society as a cultural actor and to situate it in the sphere of symbolism, where antagonism and cohesion are constructed through meaning-making. Thus, the process of analysis and findings of this paper contribute to narrative theory by expanding the exploration of the cultural foundation of social structure and contribute to the narrative method by demonstrating how these narratives deploy symbolic codes and shared beliefs about the world to categorize subjective moralities.

In this analysis, I have explored stories that were constructed for mass communication. They have the patterns that communications scholars have noted newspaper stories have: they were built by highlighting specific characters, actions, conditions, beliefs, and emotions to make sense and to be compelling, without contraction or disruptions in the story lines (Jamieson and Waldman 2002).

Further research on narratives containing the views of the different social actors is recommended. More specifically, a following step for this paper could be an analysis of the contending groups' characterizations of each other, allowing for more effective mediation in the public conversation.

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### **CHAPTER THREE: STORYTELLING AND SYMBOLIC REPRESENTATIONS IN SOCIAL MOVEMENTS' NARRATIVES ON PHYSICIAN-ASSISTED DEATH**

Antagonism and cohesion within civil society are in part constructed through symbolic representations of cultural ideas, beliefs, and moralities (Alexander 1992; Williams 2007). These symbolic representations can be expressed through stories, often personal stories, which is the most efficient way to describe lived experience (Bruner 1987). Hence, storytelling has great political power in the public discussion of social problems and affects policy decision-making because of the emotional identification that stories produce (Polletta 2006). It is common for social movement actors to use storytelling to make sense of issues, actions, and events through symbols that can be recognized and shared by movement supporters and audiences in general (Polletta 1998).

This article is thus a narrative analysis of the symbolic representations in personal stories featured by two contending grassroots organizations with prominent roles in the debate on physician-assisted death (PAD)<sup>1</sup> in the United States. The organizations in this analysis are Not Dead Yet (NDY), a disability social movement organization predominantly dedicated to opposing the legalization of PAD, and Compassion and Choices (C&C), a social movement organization that promotes and defends the legalization of PAD through various forms of advocacy campaigns, such as end-of-life care planning and legal and political advocacy. By examining the form and contents of these narratives, I hope to understand how cultural meanings

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<sup>1</sup> Throughout this article, I use the term *physician-assisted death* because this is today a common term used to define the specific type of medical intervention that is legally applied in the United States.

and emotions are constructed and strategically used by organizations whose goal it is to convince audiences that a problem of a particular sort exists and that it should be resolved in a particular way (Best 2008; Stone 2002).

However, a single issue can be represented in any number of ways, and thus *formula stories* (Berger 1997) or *cultural codes* (Davis 2002) featuring recognizable characters, settings, and plots can operate as organizational narratives for collective understandings of a social problem. The most successfully persuasive narratives are those with the most “deeply embraced cultural codes,” codes that are uncomplicated enough for a large number of people to understand them, for “persuasiveness is discouraged by incorporating contentious codes” (Loseke 2019:61).

In this article, I analyze a specific type of formula story, the *social problem formula story* (Loseke 2019), which is a story about grievances that contains cultural systems of meaning that render an issue both believable and worthy of social attention. I conceptualize culture as the webs of significance (Geertz 2003) that humans create that encompass symbolic meanings. These symbolic meanings act as an ethical guide that allows us to interact with one another inside our social groups and within the broader social structure of our time. I am interested in studying the symbolic sphere of civil society (Alexander 1992) in order to gain understanding of the cultural systems of meanings or cultural environments (Williams 2007) inside which civil society develops its engagement with and representation of a social issue.

The article is divided into four sections. In the first, I discuss narrative theory as the theoretical ground of this article, explore the role of storytelling in social movements, and contextualize the public discussion of PAD in the United States. In the second, I outline my method and narrative analysis approach. In the third, I present the findings from the analysis of

the personal narratives of the two organizations. Finally, I conclude with a discussion of the findings and suggestions for further research.

## NARRATIVES, VALUES, AND SOCIAL MOVEMENTS

### *Narratives and Meaning-Making*

Stories are prevalent in social life because we make sense of and characterize lived experience through storytelling, through narratives, for this is the way in which we give meaning and moral value to our actions and perceptions (MacIntyre 1977; Fisher 1999; Alasuutari 1997). Narrative can thus be understood as a social process or act whose function is to create meaning and emotions (Davis 2002:3).

The way in which we create meaning and emotions in stories is by using symbolic codes (Alexander 1992), which are cultural ways of thinking, and emotion codes, which are cultural ways of feeling (Loseke 2009; Elias [1969] 1994), to generate judgments of the social actors, settings, and objects of our stories. We establish binary symbolic sets of what is right and what is wrong through symbolic representations and categorizations that appeal to emotions (Alexander 1992).

To create our narratives, we draw from our cultural environments, and with our narratives we create, change, or perpetuate values and ideas that affect both the broader social culture and social order (Williams 2007). In public life, social actors frequently create personal and autobiographical stories and establish the “rightness of the self report” by drawing from the available plethora of culturally accepted stories of self, or “possible lives” (Bruner 1987:15). These culturally accepted stories of the self are part of our cultural narratives, or formula stories

(Loseke 2015), which are the stories about social life and social order that circulate in society and that attribute specific connections between symbolic codes and emotion codes.

Specific groups make claims about social problems, and to do so, they use formula stories to describe specific grievances using common cultural codes (Best 2008). These “social problem formula stories” (Loseke 2019:53) have expected characters, plots, and settings and are told to draw public attention to an issue.

Our stories are inserted in a context, a social context, and have what can be considered “narrative epistemologies,” or sets “of popular assumptions about how stories work: how audiences respond emotionally to stories, how stories convey or circumvent the truth” (Polletta 2006:21). For example, the narrative epistemology of a given context (time, institution) will have conventions as to what constitutes a story of powerlessness, awareness, or emancipation. For instance, a story about victimhood in one context, that is, operating with a certain narrative epistemology, may reflect a lack of agency or be a sign of passivity, but in another context, victimhood instead may be associated with moral responsibility and virtue, such that the victim becomes an expert and a hero (Polletta 2006). These nuances of meaning can be observed in the way narratives are emotionally structured and in their sequence of actions and events (Kleres 2011).

My goal in this study is to understand how symbolic and emotion codes are associated with one another in narrative plots to include, exclude, and categorize story characters and settings in grievance claims. My focus is on understanding the cultural circulation of symbols that bridge the individual, the institutional, and the social levels of public life and on interpreting what are the narrative plots and their emotional structure.

### *Social Movements and Storytelling*

Stories throughout all times and all places are commonly used in a broad variety of settings and levels of social life to transmit information and persuade audiences. Advertising is now predominantly based on personal storytelling (Chung, Jenkel, and McLarney 2001). In courts, storytelling is critical to life-changing legal decisions (Cerulo 1998). Storytelling in the management of organizations is highly promoted (Brown et al. 2005), and the same is true for social movement organizations (Polletta 2006), which use stories in the identity-building processes of their members (Oyakawa 2015) and in the construction and dissemination of the organization's values.

In social movements, persuasive storytelling is a key tool to construct symbolic representations that audiences can relate to and be motivated by. Because stories appeal to both cognition and emotion, they are often used to recruit new members, to encourage existing members, or to create social consciousness of a social issue in heterogeneous audiences (Loseke 2019:51). Stories serve to deliver moral lessons indicating what are the correct ways of thinking and feeling about specific issues (Polletta 2006). Organizations advocating social change author and disseminate stories in order to persuade audiences to act for the values and behaviors promoted by the organizations. Organizations adopt widely accepted values and emotions in their narratives (Williams 2007), drawing from our cultural environments' available symbolic codes, also referred to by social movement scholars as *mentalities* (Tarrow 1992) or *repertoires* (Tilly 1978). The most successful and persuasive stories are those that reflect the values of audiences (Loseke 2019).

Social movement scholars have adopted social interactionist (Goffman 1959) and constructionist approaches to study the symbolic expression of ideas and identity within



movement narratives (Davis 2002). The concept of *frame alignment processes* (Snow and Benford 1988), for instance, is used to describe ways in which social movements attempt to align their worldview with the worldviews of individuals to motivate them to participate in the movement or take action. Frame analysis of social movements “is concerned with the manner in which events are collectively interpreted, the ways in which collective action frames are developed, diffused, and acted on, and the process through which individual frames and movement frames are aligned” (Tatum 2002:180). These associations can shed light on the ways in which a need for action is established (Lipsky and Smith 1989).

This analysis looks at ways in which two social movement organizations persuade audiences through emotion narratives that construct social problem formula stories. I particularly focus on stories used by social movement organizations that appeal to both cognitive and emotional connection (Steward, Shriver, and Chasteen 2002). For this purpose, I use narrative analysis. One of my goals is to observe how organizations use widely shared and accepted values for divergent purposes through their association with different emotions.

### *Physician-Assisted Death: A Battle of Contending Values*

In 1997, the United States Supreme Court issued decisions about physician-assisted death in the cases *Washington v. Glucksberg* and *Vacco v. Quill*. The decisions did not determine that PAD should or should not be legal on the basis of the Constitution. Instead, they left the issue open for legal, social, and cultural discussion, “in the light of the differing values, historical circumstances, religious commitments and political and economic environments of the people in each of the fifty states” (Battin, Rhodes, and Silvers 1998). Thus, states are free to make laws either allowing or forbidding PAD. From the time of these decisions, the debate has expanded

significantly. At the political level, propositions for the legalization PAD have often come from the more progressive politicians (Dowbiggin 2003, 2005), and at the social movements level, it has been a cause whose majority of activists have come from the feminist movement (Wilson, Fox, and Kamakahi 1998). The subject is frequently discussed in Congress (US House of Representatives 2019), in state legislatures (Abernathy and Covich 2020), and in academia (Lavi 2009; Battin et al. 1998; Foley 2002; Balch 2017; Hanning 2019). Civil society organizations such Compassion and Choices and Not Dead Yet—which are the focus of this analysis—as well as think tanks such as the Hastings Center are also important sites of discussion on the subject.

In scholarly discussions within the United States, the main points addressed regarding PAD have been the role of medicine (Lee and Grube 2017; Weir 1992; Bachman et al. 1996; Callahan 2002); pain and access to adequate care at the end of life (Foley 2002); issues of choice and autonomy (Behuniak 2011; Sneddon 2006); the relevance of mental health (Farberman 2002); the excessive use of medical technology to extend life (Lee and Grube 2017); the danger of discriminatory biases within the medical system (Scoccia 2010), which is sometimes explained through notions about economic interests and power struggle (Kissane 2002); the risk for involuntary killing or premature self-inflicted death in the name of compassion (Pellegrino 2002); the quality of care at the end of life (Foley 2002; Hart, Sainsbury, and Short 1998); and constitutional rights (Olsen 1995; Hutchinson and Glick 2000; Wellman 2003). Often, opinions on each of these issues are polarized. However, scholars have observed two points about which proponents and opponents of legalization of PAD agree: that adequate pain control would make requests for PAD rare (Battin 1998) and that the health system of the United States needs improvement in its care for the dying (Foley 2002; Hart et al. 1998).

In sum, one of the major tasks of social movements is to bring attention to claims about social issues that movement participants believe need improvement or change (Snow, Soule, and Kriesi 2007), so that these issues can be understood and recognized as social problems and thus as worthy of attention and institutional or social action. But the task of establishing what represents a social problem requires persuasion. Audiences must be convinced that a specific issue, more so than another, represents an intolerable situation of a particular sort that requires a particular kind of resolution (Best 2008). The most potentially persuasive stories are the ones containing broadly shared views about the world (Entman 2003), especially in a world of moral fragmentation (Loseke 2016), where an issue such as PAD has become a highly polarizing matter.

## METHODS

### *Site*

This study is focused on the cyber communication by which groups from civil society establish shared understandings (Fine 2012). In order to study the connections between cultural meanings of stories shared by social movement organizations and the organizations' overall political message to external audiences, I conduct a narrative analysis of stories that define either personal or group identity, published on the websites of two organizations. My intention is to demonstrate how examining the characters, plots, and settings of stories used by social movement organizations in these virtual spaces can help us understand the value systems through which these organizations view the issues related to the grievance claims. For this purpose, I use narrative analysis to conduct a systematic empirical analysis of symbolic representations in

personal stories featured by two grassroots organizations that participate in the debate on PAD in the United States: Compassion and Choices and Not Dead Yet.

The organization Compassion and Choices is, along with Death with Dignity, one of the two best-known organizations advocating for PAD at the national level (Peace 2013).

Compassion and Choices derives from the Hemlock Society, which was founded in 1980. It later became End-of-Life Choices and merged with Compassion in Dying in 2005 to form

Compassion and Choices (Humphrey 2005). Compassion and Choices engages in public

campaigns for a number of purposes. The organization advocates to increase people's access to PAD by working to compel hospitals and health care providers to adopt the medical practice.

Compassion and Choices provides descriptions of each category of its collective action

initiatives on its webpage. In the following example, the organization describes a campaign to increase the use of PAD by hospitals:

Just a few days before the California End of Life Option Act took effect in June 2016, the Los Angeles Times reported that Pasadena-based Huntington Hospital decided to forbid its 800 affiliated physicians from participating in the law. Such a high-profile rebuke would have been a blow to the law's early implementation and acted as a contagion for other healthcare systems, so our local volunteers and staff organized community residents who were outraged by the decision to speak out. The result: Huntington reversed its position and announced it in a full-page open letter advertisement in the LA Times, telling community residents they got the message that this option was important to them.

Compassion and Choices also offers an end-of-life consultation program, and it does engage in legal advocacy, which has led it to participate in a number of legal cases. Its campaigns for the mobilization of its members have often revolved around specific figures, sometimes individuals from the general public with terminal illness diagnosis who have gotten the attention of the media due to their personal quest for PAD and sometimes public figures, such is the case of Diane Rehm, a famous American journalist from the National Public Radio network.

Among the legal cases in which the organization has participated are the Supreme Court cases of *Vacco v. Quill* and *Washington v. Glucksberg*, which resulted from two federal lawsuits filed by the organization itself in 1994. These two specific cases marked a pivotal time in the national debate over PAD. Compassion and Choices defines itself as “the nation’s oldest, largest and most active nonprofit working to improve care, expand options and empower everyone to chart their end-of-life journey” (Compassion and Choices 2021a). Its advocacy strategies include requesting that members contribute to the movement’s collective action by sharing their personal stories.

In the United States, the well-known social movement organizations that have been speaking about PAD for the past 50 years are those in favor of the practice. Detractor of PAD have not been notably organized into social movement organizations exclusively dedicated to this issue. Voices against PAD have mostly come from an array of sources including antiabortion religious organizations that are mostly dedicated to collective action against abortion. However, Not Dead Yet has emerged as a prominent secular organization—linked to the disability community—that has been visibly fighting in the public arena against this policy exclusively. NDY is the sole social movement organization in the United States that operates at the national

level and that is primarily dedicated to opposing PAD. NDY has a strong participation in court cases related to this policy and has been involved with cases in the Supreme Court. NDY has also exercised pressure on processes of policy making through lobbying. This organization was founded in 1996. In public declarations, one of its founders has identified a court decision in the case of Elizabeth Bouvai as inspiring the organization's formation (Coleman 2010). NDY opposes the legalization of what it conceptualizes as physician-assisted "suicide." NDY sees laws on this medical practice as legal instruments that allow the treatment of the suicidal impulses of people with disabilities to be different from the treatment given to the suicidal impulses of abled-bodied people. Today, the organization is well recognized around the country (Behuniak 2011). It has chapters in several states and also in Canada and the UK. NDY has been joined by other disability rights organizations in its efforts to prevent the legalization of PAD. Aside from collective action, the organization also engages in education campaigns and legal advocacy. It defines itself this way:

Not Dead Yet is a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill and disabled people. Not Dead Yet helps organize and articulate opposition to these practices based on secular social justice arguments. Not Dead Yet demands the equal protection of the law for the targets of so called "mercy killing" whose lives are seen as worth-less. (Not Dead Yet 2020b)

Compassion and Choices and Not Dead Yet are also recurrently referenced as the two main advocacy actors in the debate on PAD in articles published by the Hastings Center, one of

the most prestigious bioethics research institutes in the United States (Levin and Fleischman 2002).

### *Data Selection and Classification*

The data for this analysis consists of personal stories and opinion articles written by members of the social movement organizations Compassion and Choices and Not Dead Yet. On the website of these organizations, visitors can find personal stories that define what the problem at hand is. On the Compassion and Choices website, there are numerous stories by people who advocate for the policy's legalization because they themselves have requested or campaigned for this medical intervention. They are testimonies of the lived experience of terminal illness and the desire to take control over one's death. On the Not Dead Yet website, on the other hand, the stories are harder to find: they are embedded in articles written by members of the organization that the organization has created links to. These stories are about disability and stigma, the experience of discrimination within the medical system and in society as a whole, and forms of resiliency.

Compassion and Choices presents the stories as an integral component of the website's content; they are presented at the frontstage of their collective action campaigns (Goffman 1959). These stories are an important element of the organization's advocacy strategies, and they continue to grow in number as times goes by. In May 2020, there were 63 such stories in total, and by October 2022, there were 119, all of less than one page each. The stories are placed as a central element in the design of the home page of the organization's website, which features only two subtitles: "Latest News" and "Stories." The full compilation of stories can also be accessed in a section of the website formerly titled "Take Action" and currently titled "How You Can Help." A drop-down menu in this section contains three options: "Volunteer," "Contact Your

Legislator,” and “Tell Your Story.” Inside the section “Tell Your Story,” there is, above the stories themselves, a short text that reads as follows:

The power of personal stories to inspire and drive change is undeniable. That’s why Compassion & Choices would like to invite you to join our network of storytellers to help educate and empower those seeking the best possible healthcare. Share your story, today.  
(Compassion and Choices 2021b)

In the case of Not Dead Yet, the stories are presented in articles from blogs linked to the NDY website. In May 2020, there were 48 linked articles, 33 of which contained personal stories, and by October 2021, the number of article links has remained the same. Similar to the value of “action” given to the stories on the Compassion and Choices website, the Not Dead Yet article links are also published in a section titled “Activities” (which lists the advocacy activities of the organization). The drop-down menu of these activities includes a subsection called “Articles,” which is where these links appear. In a similar layout to that of the Compassion and Choices page called “Stories,” Not Dead Yet’s page called “Articles” receives visitors with a descriptive text that reads as follows:

Not Dead Yet leaders and our disability rights partners are invited to provide keynote speeches, plenary remarks, guest lectures and panel presentations at conferences, universities and public policy forums regarding NDY issues. They also provide workshops and exhibit booths at conferences and public events. (Not Dead Yet 2021)



All the articles included in this list of links (53 articles ranging from one to three pages each) are written as opinion pieces. This factor does differentiate these narratives from those published on the Compassion and Choices' website. Nonetheless, NDY's "articles" also contain personal stories. Both organizations treat these stories as an integral part of their collective action, a treatment that is observable in the layout and introductory texts of the pages.

The authors of stories on the Compassion and Choices webpage include people who identify as family members of people with terminal illnesses, as people experiencing a terminal illness themselves, and as health care providers. The narratives from the Not Dead Yet webpage are all written by people who identify as people with disabilities (terminal illness is not a relevant category in these narratives).

For the thematic classification of the data, I saved all the narratives to PDF documents, which I initially stored and coded using the qualitative analysis tool NVivo. This helped me determine the recurrence of themes. I anonymized all the people who appeared in the stories by replacing their names with pseudonyms and eliminating markers of place and specific age to preserve confidentiality. I then proceeded to conduct numerous close readings of each of the stories to understand the narrative emotion (Kleres 2011) and the story elements—that is, characters, plots, and settings.

In this article, my goal is to examine how the social problem formula stories are constructed through the plots and attributes of characters (Loseke 2019) and the various value judgments assigned to the different elements in the story. I also strive to understand the narrative epistemology (Polletta 2006) that these stories encourage. I consider questions regarding the logical, emotional, and moral evaluations that the narratives encourage, questions such as: What are the sets of popular assumptions about how moving stories about physician-assisted death

should work (Polletta 2015)? Which emotions appear in the narrative plots of these personal stories (Kleres 2011)? What do the stories tell us about the sociocultural context in which they are produced (Best 2008)? and What are the most broadly shared codes in these stories (Loseke 2019)?

## DATA ANALYSIS

In this section, I show how the stories featured by Compassion and Choices and Not Dead Yet encourage, through formulaic stories, awareness of the social problem that each organization promotes in relation to the legalization of physician-assisted death. Both organizations present stories of complex and materially impactful issues. I first describe and analyze the overall social problem formula story constructed by the various narratives featured on the Compassion and Choices website, and then I do the same with the narratives on the Not Dead Yet website.

### *Compassion and Choices*

As noted earlier, the Compassion and Choices' stories are part of this organization's collective actions in its effort to promote the legalization of physician-assisted death in the United States. I now describe some of the patterns and characteristics of these narratives. My goal is to learn about the ways in which the organization defines the problem that it seeks to solve through the legalization of PAD. Drawing from narrative analysis methods (Kleres 2011; Loseke 2019; Franzosi 1998), I analyze three specific elements: the characters, the plots, and the settings.

#### THE CHARACTERS: GOOD FOLKS WHOSE IDENTITIES HAVE BEEN SPOILED

In the Compassion and Choices stories, people describe themselves in several ways. A recurring pattern of self-description consists of references to wonderful lives, underscoring the values of happiness, fulfillment, and ability, but always in the period prior to the diagnosis of the illness. These descriptions of the experiences or conditions define the characters as they “used to be,” before the illness ruined these identities. In the following example, a narrator whose experience became the forefront personal story shared by Compassion and Choices in the organization’s efforts to legalize PAD, describes herself as a young person who used to have plans for a happy family life:

On New Year’s Day, after months of suffering from debilitating headaches, I learned that I had brain cancer. I was in my late twenties. I’d been married for just over a year. My husband and I were trying for a family. (Natalie)

Another narrator looks back at himself and makes the positive remark that he was a strong and hardworking man before he laments the present:

In my career as a stonemason, I carried 80-pound bags of cement mix every day. Now I can’t even get in or out of bed without help. (Conrad)

The following narrator describes the case of her grandfather and stresses the virtues of a loving, generous, and lively man:

Grandpa was a lover of life. He was a teacher before he retired and, throughout his life, donated generously to nonprofits. Far into his 70s he continued to follow his passions of family, painting, cycling and cooking delicious food. (Bethany)

This narrator describes how her sister used to be:

Let me tell you a little about my sister. ... She was a stay-at-home mom who, with her husband of 50 years, raised three wonderful, strong children. Her passions in life were gardening, birds, and the Green Bay Packers. (Mandy)

#### THE PLOT: DONE FIGHTING

The authors describe processes of physical suffering and, in most cases, the exhausting fight to overcome illness. People with terminal illnesses in these stories have courageously endured hardship due to their lack of health and want the last moments of their lives to be pleasant; they want to die in the company of loved ones and away from bureaucratized processes and institutional entrapments. The following narrator, for instance, speaks about the endurance of physical hardship. Her sister traversed a very difficult process of illness before deciding to die at home near her family:

[She] was able to live alone in her home with some help for more than a month. When it became clear that she needed help 24/7, her daughter and I alternated caring for her as she became progressively weaker, until she could no longer move her body or care for herself in any way. One morning, two months after her diagnosis and initial request for a

prescription, as she awoke, she said to me, “Today’s the day.” Her two sons, who had been visiting frequently, were at their homes in other states. I said, “Let’s see how long it will take to get the boys back.” She replied, “OK, tomorrow.” (Annie)

Suffering—often represented by physical weakness and dependency, less often pain—is the central drive for people’s desire for PAD. A recurring plot in these stories is that people only choose PAD after having been confronted with long and cumbersome battles against their disease. People only choose PAD at the end of journey of suffering, not out of cowardice, which would be morally wrong, but in a quest for dignity. PAD is not “suicide”; it is solely the hastening of a certain and terrible death. Not being able to care for oneself is often the final sign for the person with the terminal illness to decide to end their battle. In the above sample, we also see a common element in the plot of these stories, which is dying in the company of family. A good death is one where people are surrounded by loved ones.

In another story, the narrator spells out his struggle, telling readers that he has done “everything in his power” to prolong his life, again a sign of emotional and moral soundness, for the narrator has had the courage to fight the illness:

Since [several years ago], I have been battling metastatic prostate cancer. I’ve been through multiple therapies and chemotherapy treatments and have done everything in my power to try to prolong my inevitable death from the cancer that has now claimed my body and stolen my quality of life. (Conrad)

Aside from the courage to fight the illness, another important value in these stories is the lack of fear of death. Death is not the source of fear; dying without control of one's body is. The law is thus presented as a solution for such lack of control. The narrator just quoted adds the following, making reference to the PAD bill in his state:

I am not afraid of death. I am afraid of the pain and suffering of dying from cancer.  
Passing this bill would provide comfort and peace to terminally ill residents just like me.  
(Conrad)

Frustration and sorrow are underlined when lack of access to PAD dominates the story:

Despite all the careful planning, his passing tore my family apart. My parents' grief is steeped in the horror of what his last days were like, of wondering what his final moments held and bitter pain that they were not there to provide comfort or assurances.  
And why? It's all so very unnecessary. (Sylvia)

In these stories, good people who fight long years against a disease, who do not fear death but only fear losing their capacity to care for themselves, would be saved by PAD legislation, which could give them some well-deserved peace before death. Not allowing PAD is described as a fundamental injustice, as John describes in this quote:

There's no need for anyone to suffer like that. ... Our experience was horrid. I can't think of a single person I would wish this on. It was such a hideous process to go through with

my wife. Knowing she was ready to die, and there was no way I could help her, I'm left feeling like I failed her. It was such a tragic ending for such a beautiful person. My wife deserved to make her own decision. (John)

A nuance in this plot is not only that PAD should be legalized but also that the laws should allow for easy access and simple processes to obtain the medication. A narrator describes how her husband experienced a great number of obstacles to obtaining the PAD medication. The journey to a good death may be one full of obstacles, a terrible long-lasting disease, a lack of laws to facilitate the process of hastening death when one feels ready to die, and medical professionals capable of standing in the way of a simple process by making use of a bureaucratic system, even after laws try to facilitate the journey:

Neither of us understood very well that you had to jump through some hoops to access medical aid in dying. As [his] health continued to deteriorate, once it was clear that [he] only had six months or less to live, we talked to his ALS doctor to start the request process. By this point, [he] was talking through the computer and he told her that this is what he wanted to do. She threw up every roadblock imaginable. She tried to talk him out of it. I was really disappointed. [He] did not waver and she finally agreed to move forward with his wishes. (Laura)

A similar aspect of the plot is expressed in the following narrative, where the narrator expresses gratitude that her husband was able to access PAD, yet she also denounces a disparity

between the law and the application of the law, as medical protocols made the process more difficult. The implication is that people should have easier access to PAD.

I'm so grateful that my husband was able to utilize this compassionate law, however, our experience should have gone more smoothly. We relied on our hospital provider for direction. I learned later that their protocols do not mirror the law's protocols; our provider imposed additional limitations on the process. For example, their doctors are not allowed to provide teleconference calls in lieu of an office visit. This imposed a significant hardship on my husband that could have been avoided. If only I had known more about the law and how it works, I believe the process could have been easier on us.

(Lucy)

In the following sample, the frustration with the process to choose PAD is explicit. This quote also shows the recurrent negative reference to physical impairments. In this case, the person with the illness is described as "wasting away":

At the second appointment, [my husband's] ALS doctor confronted me and told me that I seemed angry. I, very justifiably, replied, "I am angry. This has been living hell. I'm watching this man, whom I love, deteriorate and waste away in front of my eyes. I can't do anything to help him, and you have thrown up roadblocks at every opportunity."

(Mary)



In the stories in favor of PAD, life with illness is characterized as a threat, and thus the fear of illness is characterized as moral. PAD thus becomes the solution for courageous heroes who, tired of futile battles against disease, are confronted with legal and bureaucratic barriers in their path toward the liberating act of controlling their own death. As we will see in the next section, the stories against PAD seem to respond to this notion of having to liberate oneself from the “horrors” of living with a disability. In those stories life with illness is instead characterized as complicated mainly by social discrimination and alienation, not the physical conditions of the individual. PAD in those stories is thus characterized as the ultimate threat to the resiliency of people who must live in combat against an oppressive society.

#### THE SETTING: DESIGNING THE STAGE OF A GOOD DEATH

Most of the Compassion and Choices narratives make reference to the moment of death when PAD has been chosen. The setting is thus the specific state where the policy is legal and, more narrowly, the person’s home. In the following example, a woman who moved to Oregon—where PAD was already legal—and is able to choose PAD to end her own life describes what she envisions will be her own moment of death, when she will be in command, will be empowered by having agency, and will thus be surrounded by loved ones who will accompany her through a peaceful last moment:

When my suffering becomes too great, I can say to all those I love, “I love you; come be by my side, and come say goodbye as I pass into whatever’s next.” I will die upstairs in my bedroom with my husband, mother, stepfather and best friend by my side and pass peacefully. (Natalie)

PAD in these narratives is a symbol of agency to choose, and the place of death is part of this choice. Being at home is associated with happiness. At home, people can die peacefully surrounded by loved ones. The happiness of dying at home is either granted or denied, as some of the storytellers and protagonists of the stories live in states where PAD is legal and have chosen it, and some do not. Symbolic codes such as family reunion and peacefulness, associated with emotions of love and contentment, surround the image of home.

In another story, narrated by a sibling, the principal setting is not a physical place but the company of family. The person with the terminal illness dies accompanied by family and friends in an event full of symbols of joy, a last delicious meal, and friends' participation in something like a ritual:

I was with [her] on her final day, as were 12 of her favorite family and friends. Family that couldn't make the trip Skyped in to say their final goodbyes and we love yous. Two of her best friends prepared [her] aid-in-dying medication, which was mixed with apple juice, while [she] enjoyed her last meal. She had a wonderful breakfast of a cinnamon roll, fresh pineapple, and Dom Perignon, per her request. Her last moments were spent being hugged and kissed by friends and family, surrounded by beautiful, fresh flowers. I held [her] hand as she drank her apple juice, told her she was strong and brave and my hero, she closed her eyes and 10 seconds later her pain was over. She died peacefully surrounded by family and friends. (Jamie)

Most people in the United States today die in hospital settings (Ball 2017), and the recurrence of the symbols of home and family in these stories speaks to a cultural narrative of discomfort with that fact. The symbolic value of “home” is fundamental and at the same time not a problematized factor in these stories. There are no queries or concerns related to solving the logistical aspects of caring for people who need physical assistance due to illness or disability in domestic settings because the problem in these stories is having to live with illness or disability. Time, in this regard, plays an important role in these stories. In a way, the narrative presents home and the company of loved ones as components of a finite ritual in the face of hopelessness. Shortening the time that one lives under circumstances of dependency on loved ones, however, is a fundamental urge. However, there is no discussion about adaptive changes to the physical space to address changes in the physical conditions of the body.

#### SUMMARY: A MORAL CHOICE

The Compassion and Choices stories assert that PAD is moral in several ways. One way is by responding to the potential character flaw of not having fought enough for one’s life: the characters in these stories try hard to combat their illnesses before they choose PAD. The final gathering with family is of great importance because it symbolizes a significantly valuable loving moment with those who are closest but also because the presence of others validates the process as one that is free of the broadly shared understanding of suicide as a selfish act, or one born out of weakness of character. Avoiding suffering from physical pain and avoiding physical dependence on others are the central themes, and though there is a sense of community symbolized by the family gathering in the moment of death, community living is also rejected in the expressed aversion to physical dependency on others.

The central claim in the Compassion and Choices’ narrative is that people should have full control over their bodies in the face of imminent death and that choosing a hastened death may be the most rational choice. Having control means being able to choose to avoid processes of painful and difficult illnesses, which are conceptualized as “needless.” Supporting ideas for this claim are that people should not have to die alone and that medical institutions are the wrong place to die. It is morally wrong for medical professionals to make the process of PAD difficult.

In the personal stories analyzed in this section, narratives describe emotions of nostalgia, courage, or frustration, among other emotions, and denote commonly held beliefs about illness and the end of life. These stories introduce an understanding of death as something that you do and not as something that happens to you (van Wijngaarden, Leget, and Goossensen 2016). Through personal characterizations, the authors describe purely good lives of purely good people. The characterization of goodness—done through the description of people’s emotions and character qualities—accentuates the deservedness of the good elements in people’s lives, such as beautiful families or great careers. The majority of these stories have a similar structure, in which the life of a good person is described, then the process of fighting the illness, and finally the process of death. This structure perhaps responds to popular assumptions about what an emotionally moving story should be (Polletta 2015).

### *Not Dead Yet*

The Not Dead Yet stories are less obviously part of this organization’s collective actions than the stories on the Compassion and Choices website are. This is because the stories themselves do not seem to be mediated beyond their selection. They are not uniform in design and structure, but this lack of organizationally directed uniformity makes the recurring patterns shared by them

significant, for they happened organically. As with the Compassion and Choices stories, I analyze first the characters, then the plots, and finally the settings in these stories.

#### THE CHARACTERS: REGULAR AND REASONABLE FOLKS UNDER ATTACK

In the Not Dead Yet stories, people describe their identity through markers of ordinariness. Just like the characters from the Compassion and Choices stories, these stories' central characters have culturally available and canonical structures of lives (Bruner 1987); in other words, these stories are about regular people. The stories focus on mundane activities but also narrate in detail physical characteristics and impairments. They describe the social experience of disability and explain, through anecdotes, the experience of stigma and discrimination. The stories appeal to broadly shared values by using symbolic codes of commonly accepted positive life conditions, such as having a loving family and marriage, being employed, and receiving an education, as well as serving society:

I'm 44, married, a PhD student and freelance writer. I sing in a rock/pop band and mostly love my life. I have been disabled since I was four; I use a wheelchair and rely on PAs to assist me with pretty much everything. (Mary)

In the characters' routines, disability is not presented as a tragedy but as an intrinsic part of everyday life:

I'm a gainfully employed, tax paying, property owning, Texan with Spinal Muscular Atrophy, a very severe, progressive, rare, and genetic neuromuscular disability. I use a

power wheelchair and require help from an in-home healthcare provider day and night to get in and out of bed, showered, dressed, prepare meals, and perform other activities of daily living that I do not have the strength to do. At night, because my lungs have gotten so weak, I use a ventilator to help me breathe. Despite my physical disability, I hold two master's degrees and a teacher's certification. I taught Texas children for seven years full-time until my disease progressed to a point when I had to leave teaching and find other full-time work. Now, I work for Austin Community College and advise students, helping them to become educated and skilled members of Texas's workforce. (George)

In some cases, as in the following sample, disability is denoted as a source of empowerment or joy:

Despite my bad day, I still marvel at my body. It has been through the wringer. I often wonder how have I survived into middle age. I never thought I would turn 21 years of age much less settle comfortably into my 50s. I survived three massive spinal cord surgeries as a teenager, dozens of spinal taps and countless medical procedures as a child, a stage four wound on my hip, and a heart attack. This cavalcade of medical woes has not diminished the feeling that my body has exceeded my wildest expectations. (Andy)

The depiction of the body as a source of joy is not obscured by the mentioning of the hardship of the "countless medical procedures," a reference that does not make it a narrative of negativity but of the achievement of "survival."

There is an appeal to empathy in the act of referencing marks of “regular lives” in the following story, which the narrator tells us is a made-up story. An appeal to complicity is made through the humorous tone.

Marie grows up and starts attending college. She meets a guy and they hit it off so well that soon they are like most college kids these days and having horny sex. All of Marie’s friends tell her to go to Planned Parenthood to get on birth control. ... The doctor enters the room and completely looks past Marie to her friend. When her friend tells the doctor that she’s at the office to accompany Marie, the doctor looks at Marie dumbfounded. Marie explains that she has Spinal Muscular Atrophy, which is, “kind of like Muscular Dystrophy.” She claims that even though she uses a wheelchair, is 65 pounds, and can barely move, she is sexually active and trying not to get pregnant. The doctor’s mouth drops, and he thinks back to all those years of watching the Muscular Dystrophy Association’s Labor Day Telethon. Wait, he thinks. Aren’t these kids supposed to be dead already? Aren’t they terminal? He figures Marie is an unusual case. (Linsey)

An important element to note about many of these stories is the use of irony and humor; connoting what is contrary to what “might be expected” is a recurrent rhetorical figure in these stories, and joking is common, as in the description of the doctor’s assumptions above. Marie’s enthusiasm for sex in this made-up story is also a counternarrative to cultural assumptions about disability.

Society as a whole is referenced as the collective villain in the following quote, and people with disabilities are the victims of maltreatment for pointing to the taken-for-granted injustice:

Opposition to assisted suicide is somehow seen as in bad taste—a characteristic of an unreasonable person. When I state my opposition to assisted suicide people are perplexed. ... Some people become confrontational and nasty. I have repeatedly heard others tell me “Just because you want to live with a disability does not mean others want that life.” Unsaid is the assumption my life is miserable and less valuable. (Adam)

The main characters in these stories are recurrently the victims of discrimination. They are also just regular folks with completely reasonable demands. The lists of regular human activities are a response to culturally prevalent assumptions about an equivalence between disability and tragedy and perhaps a comment on the circulation of these assumptions in the PAD debate.

#### THE PLOT: THE DAILY STRUGGLE OF THE BLAMED VICTIM

These stories are about an inhospitable world where the deficiency of public infrastructure is the norm. Regular daily activities may be affected by the acute distress generated by a culture of hatred toward people with disabilities, who are maltreated through neglect, violence, or disregard. In the following story, a man has difficulty doing regular activities because of the distress this causes him:



I had to do something inconsequential yesterday. I needed to go to the apartment building office where I live and put in a simple work request. I planned to do this at 9am shortly after the office opened. I went to the office in question at 4:30pm. I did not exit my apartment until late afternoon because I was overcome with anxiety. When one has a disability, going outside can be dangerous. I do not typically fear for my physical safety. I fear and dread what people will say to me. I feel as though I am a Martian living on the planet Earth and the Earthlings that surround me hate my existence. Worse, they have the means to easily destroy me. (George)

The inhospitality and deficiency of public infrastructure is completely unproblematized by society, as signified by the ignorance of medical professionals in this story about a visit to a hospital:

I was repeatedly told “we have never had a paralyzed patient like you” or “no one has ever asked such questions.” My questions were not obscure. What sort of access is present on the cardiac floor? Where is a bathroom I can access? Will diagnostic equipment be accessible? What became evident was not shocking—no protocol existed for people like me. (Mark)

These narratives underscore how deep-rooted the culture’s discrimination is and the risk that it represents for people with disabilities. Concerns with access to health care are a prevalent symbol of the lack of trust in the medical system:

I was born nearly 55 years ago with spinal muscular atrophy, a congenital, progressive neuromuscular weakness akin to muscular dystrophy. Without extensive daily interventions—hands-on (and expensive) assistance with bathing, dressing, toileting, and feeding, as well as breathing treatments, wheelchair maintenance, and so forth—I wouldn't last long. In fact, before recent medical advances, half of the infants diagnosed with my condition perished before age 2. Their hearts and lungs simply became too weak to go on. The knee-jerk questioning of whether my life is worth saving drives my opposition to the legalization of assisted suicide. And I know I'm not the only one who's experienced this kind of dismissive attitude, the subtle pressures, and invisible coercions to unburden others. (George)

Discrimination can be fueled by economic interests that pile on stigma. Blaming the victim is the norm:

I experienced such contempt and coercion while fighting for treatment for my elderly mother, who suffered from vascular dementia and a severe heart condition. As her health care advocate, I was continually and repeatedly harassed, bullied and threatened by various health care professionals at the hospital to “let her die.” As a Medicare/Medicaid patient, she was costing them too much and her life was not valued. (Nancy)

Direct experiences with PAD are few and far between in these stories; PAD is mostly referenced as an abstract concept. Yet in the following narrative, a narrator describes being appalled by a publication in a mainstream magazine. The narrator identifies in the scene both the

commodification of the serious matter of death and the cruelty of ridiculing a person with disability in that context:

A few days ago, I read in an online magazine, “Rebirth Ceremony” party goer’s personal account of the party. As you would expect, I was appalled and taken aback. ... The long essay gushes over how sad and wonderful the ceremony was. It is replete with a description of a fashion show in which party goers try on the woman’s clothes. Yes, the author apparently fell in love with a vibrant red Donna Karen wrap dress that was difficult to figure out how to wear. ... The woman, you see, has ALS and is terminally ill. Clearly, she could never enjoy wearing such a “frock.” I breathlessly read that “She groans in frustration. She’s unable to talk because she is in the final stages of ALS.”

(Alice)

The plot defines the underlying concern about PAD: the system does not work properly, and ignorance reigns among medical professionals, but also society as a whole is affected by a disregard for and even hatred toward people with disabilities. In consequence, people with disabilities, who already have to struggle to survive, are imminently threatened by PAD legislation.

#### THE SETTING: THE WORLD AND ITS HOSPITALS

The broken world as a whole is the setting of these stories, but doctor’s offices and hospitals are frequently broad to the front of the stories. The implication, for example, in the following story is that the lives of people with disabilities are less valuable for health care providers in hospital

settings and that this may be true regardless of how well equipped or not the hospital may be. The risks in these settings may also be worsened by individual conditions, such as not having people who care for your well-being being, or not being emotionally stable oneself:

All I remember is passing out in a hospital bed. My wife says I called out for my mother, who died in 1981. It looked like I was going to join her. The bleeding was set off a few days earlier by a surgeon's blunder, in another hospital, during an unrelated gastroenterological procedure. In context, I was lucky: I was in a well-equipped, big-city medical center. I was quickly surrounded by medical staff. But there was a delay. "Is he full code?" someone needed to know. Again, a rough translation: Should the hospital proceed with lifesaving surgery, or was I DNR? Meaning: Do not resuscitate. Fortunately, my wife was clear about my desire to live. We'd discussed this possibility before. And, in time, I made a full recovery. But not everyone has a significant other like mine. (Paul)

The medical staff, who would not necessarily have resuscitated the man in this story had his wife not been there, represent the risky nature of hospital settings. The health care professional's biases and disregard for the value of the lives of people with disabilities is recurrently symbolized as a factor that heightens the vulnerability people may face in these settings, where disability may signify for the medical professional a long list of devaluing social positions:

When I engage health care professionals, I spend much of my time assuring them that my life is worth living. Health care workers make all sorts of assumptions. Most assume I am

unemployed. Most assume I am not independent. Many are shocked when they learn I have a PhD. I am regularly told I am inspiring because “I could never live with such a severe disability.” The fact that I can drive is nothing short of miraculous. When I state I am a father I am asked: “So how many years after your son was born were you paralyzed?” The message is not subtle. I am not parental material. I am not independent. I am not employable. Ableism is rampant in our health care system. (Mark)

Anger, distress, and fear are triggered in medical settings, but this is just a continuation of what happens in the street. What happens in hospitals happens because it also happens in the street, and the social actors who perpetuate the violence may be the ones who are supposed to help you. They can be anyone, and you may find them anywhere, making all places dangerous places. The culture may be changing, but it has not yet changed enough; and being alone in the world is scary because the hatred is willfully ignored:

I look to my right and see a well-dressed businessman in an expensive suit and tie. ... He sneers at me in complete and utter disgust. Here it comes, I think. He did not disappoint. “Why don’t you people just die?” His head shakes: “What a waste of life.” The light turns green and off he goes. ... People only make this comment when I am alone and assumed to be an easy target. Such bigoted thoughts are not socially acceptable. However, alone at a corner, I am an easy target. Strangers feel empowered to be as cutting as humanly possible verbally and physically. There is no question in my mind this man and others wish I did not exist. ... If I tried to report this man I likely would be

laughed at. The police have better things to do, and I have no doubt any officer that would show up has no clue what ableism is. (Rob)

#### SUMMARY: THE DAILY STRUGGLE OF DEVALUED LIVES

The Not Dead Yet stories are primarily about the experience of discrimination. They advocate for a general change of culture, for they imply that the desire for PAD comes predominantly from a social aversion to disability and all that it can imply, including the experiences of pain or interdependence. These narratives describe a prevalence of ableist ideas and emotions in the world, and they describe the lives of people who are trying to go about their daily experiences while coping with issues of body pain or needing assistance. PAD is not referenced in anecdotal contexts in these stories beyond the experience of conversations about or of emotions caused by the representation of the topic in public life. A common setting is the hospital, where neglect and biases are the norm. These stories are about ableism and about how this form of social discrimination is taken for granted and unquestioned.

#### DISCUSSION

Researchers in the United States have been working to capture nuances in the debate about physician-assisted death since the issue gained public notoriety in the late 1990s with the Supreme Court's decisions in the cases of *Washington v. Glucksberg* and *Vacco v. Quill* (Battin et al. 1998; Foley 2002; Balch 2017; Hannig 2019). Through these efforts, specificities of the discourses and narratives of both sides of the debate have been examined. An important understanding that emerged from these efforts, for instance, has been of the shared concern, on both sides of the debate, for the medical treatment of pain (Battin 1998) and the quality of the

medical care for the dying (Foley 2002; Hart et al. 1998). Scholars have also noted that both sides of the debate address the concepts of dignity (Behuniak 2011) and individual autonomy (Kalwinsky 1998), even if each side approaches these concepts from a fundamentally different perspective.

The stories in this analysis demonstrate some of these common concerns, the concern for the quality of medical care, for example. The different perspectives in relation to dignity and autonomy are also present. The difference seems to be wrapped in a moral dualism that has been identified as being at the core of American culture since its inception (McFarlane 2019; Howe 1998): the dualism between individualism and communitarianism. The Compassion and Choices stories claim that there is a need for people to be able to make decisions about their own bodies and to have the right to hasten their deaths before they become dependent on others. The Not Dead Yet stories, on the other hand, denounce that the medical system in the United States is not sufficiently available to everyone and also that the culture of ableism makes people with disabilities feel like a burden. The first stories are concerned with a need for control over personal choices, a petition for less institutional intervention in people's lives, and the second stories denounce institutional neglect and discrimination, a petition for further institutional assistance in people's lives.

A neglected aspect of analysis in works about PAD has been the processes by which each side of the debate establishes its system of values. One such process, as demonstrated in this article, is the use of persuasive storytelling by social movements to establish specific value systems (Loseke 2019). The narratives in this analysis show how stories can transmit complex meaning-making and moral evaluations of lived experience (MacIntyre 1977; Fisher 1999; Alasuutari 1997). One can also see in the stories promulgated by Compassion and Choices and

Not Dead Yet how narratives can operate as social processes by which groups create both meanings and emotions (Davis 2002:3). By doing so, they create emotional attachment to specific meanings and guide understandings and feelings that people *should* have toward a public policy.

Personal storytelling used by the two social movement organizations in this analysis shows how these groups, through their virtual spaces, mold and share the underlying ideas and emotions that ought to guide their group's grievance claims. To read these personal stories is to put oneself in the storyteller's shoes. Thus, this analysis encourages us to better understand what each group wants and fears, because emotions in stories show us the binary symbolic sets of what people consider right and wrong (Alexander 2010), allowing us to see complexities in their worldview.

We see in all the stories in this study how the convention of their narrative epistemology (Polletta 2006) is to associate victimhood with moral superiority, not with weakness, and what lies behind these associations are radically different evaluations of disability and impairment. The stories share the positive characterization of family and the negative characterization of the medical institution, and these similarities between the stories speak of broadly shared values of our current times in the United States.

One important element stands out in these stories. The two sides of the debate are not speaking to each other. The NDY stories do not address the need to be in control of one's death and in the company of family at the moment of death or that, along with physical independence until the last moment of life, those elements constitute the idea of a good death, which is the centerpiece of the C&C story. On the other hand, the C&C stories do not address ableism at all. There is no response to the claim in the NDY stories that people with disabilities would be more



vulnerable to fatal mistakes in the use of PAD because of the taken-for-granted ableism that prevails in society.

To make a position toward PAD compelling, both groups appeal to similar emotions and, in some cases, similar cultural tropes. Being close to family and having friends and hobbies are cultural cues humanizing both positions, contextualizing the stories in traditionally “good” life configurations. However, the value system that is weaved by each of the two sets of stories in relation to PAD is radically different. For C&C, legalizing PAD is the only moral answer, and for NDY, legalizing PAD is morally wrong and dreadfully dangerous. The stories are what Polletta (2006) calls “speak-outs,” by which members of each of the groups establish templates for how to express the position of the group through a personal story. These speak-outs establish the value system of each of the organizations in relation to its grievance claims.

This article contributes to further understanding of the way cultural representations and personal narratives can affect material life by influencing policy-making processes. It also expands the literature on the topic of physician-assisted death by offering a review of opposing perspectives, and it contributes to the social movement literature with an empirical analysis of the use of emotions in narrative by two contending social movement organizations. This work also offers a practical contribution to the narrative analysis of policy-making processes, and its findings can inform the specific case of physician-assisted death as a public policy by illustrating some of the overlapping concerns shared by opposing sides of the debate and some of the issues left out by both sides of this public discussion, thus offering opportunities for the improvement of the policy-making process itself.

This article extends research on the symbolic value of narratives by exploring ways in which emotional significance is attributed to the plots of stories; the ways in which stories

contain expected characters, plots, and settings; and the ways in which contexts determine how stories are interpreted, for every context has expected plots that will be evaluated in socially shared ways. Though previous studies on physician-assisted death have explored the arguments of a social movement organization in court cases (Tatum 2002) and the ideological frames of physician-assisted death of social movement organizations (Behuniak 2011), the cultural construction of the contending narratives remains largely unexplored.

Further research to expand the knowledge on this debate in the United States could examine the stories brought by the organizations Not Dead Yet and Compassion and Choices to pivotal court cases in the national debate on PAD.

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## **CHAPTER FOUR: THE CONSTRUCTION OF PUBLIC NEEDS THROUGH SELF-NARRATIVES: THE CASE OF PHYSICIAN-ASSISTED DEATH IN MAINE**

Public debates about social policy are empirical windows into shared beliefs that circulate in the social context in which the discussions take place. Any given public policy debate can shed light not only on issues directly related to the policy itself but also on more general social values shared by the community. When discussing policy, communities use definitions of “what it means to be human” and what it means “to have dignity,” in order to negotiate and establish the community’s patterns of public needs (Stone 2002:81). In doing so, social actors speak of their views and emotions and define their expectations for social interaction. In the United States, the legalization of physician-assisted death (PAD) has generated a debate of this sort and has thus become a publicly available empirical ground to study socially circulating ways of thinking and feeling about the end of life, health and illness, family relations, the medical profession, and constitutional rights, among other issues, but also the meanings of being human and having dignity.

This article is one section of a multilevel analysis of the PAD debate in the US. In this article, the unit of analysis is testimonies from the public archive of the 2019 legislative hearing on the legalization of PAD that took place in the state of Maine, right before a bill to legalize PAD was passed in that state.

I share the ideas of narrative scholars who have observed that when social policy is created, all types of social actors, including institutional powers, elites, advocacy groups,

individual constituents, and the media, contribute to shape the policy-making process and that they do so, in part, by making use of narratives that are cultural (Loseke 2019). Narrative scholars have also argued that humans are storytelling animals (MacIntyre 2007) who characterize their actions and lived experience by performing dramatic narratives (Fisher 1984). Building on their work, I employ the method of narrative analysis to tease out the meaning-making processes in this PAD debate.

Given the salient concern in this policy discussion with the moral duties of medical professionals and the social status of people with terminal illness, I have focused my analysis on stories related to these two issues and character types. The broad organizing question of my inquiry is: What do the personal stories in the debate on PAD tell us about broadly shared cultural beliefs and emotions regarding social needs in the realm of health and illness? Through this analysis, I have identified two distinct sets of narratives—one set in favor and the other against PAD—that seek to persuade audiences by making use of *formula stories* (Berger 1997). Embedded in the narratives are contradictory meanings of the notions of choice and dignity and public needs claims (Stone 2002) that are seemingly mutually exclusive and that pertain to issues of medicalization, the economization of the end of life, and ideas about what constitutes a “good death.”

This analysis contributes to the study of emotions as cultural phenomena (Kusenbach and Loseke 2013), the use of narrative analysis in the study of public policy (Hajer 1995; Fischer 2003; Roe 1994; Stone 2002), and the development of a constructionist social problems approach to the study of health and health care (McKinlay and Marceau 2000). Constructionist approaches, which remain largely unexplored with regard to PAD, may constitute a timely effort,

considering the high number of legal initiatives and new legislation around the globe and within the United States that seek to legally protect this medical practice.

In the next sections of this paper, I first explore methodological propositions that serve to develop research strategies to study ways in which culture permeates policy making. I discuss narrative analysis and theory, traditions in policy analysis, the use of personal stories in policy processes, and social problems approaches for the study of claims-making in such processes. Second, I review some key interdisciplinary studies on the subject of PAD, paying special attention to those that address issues of social values, and I tie these works' findings to notions explored within the health and health care literature. Third, I discuss my data selection and analysis methods, as well as limitations of the data, and describe in more detail characteristics of and the reasoning for choosing the specific site for this study. Then I present my findings, followed by a final discussion and suggestions for future research.

## ON THE STUDY OF THE INTERSECTION OF CULTURE AND PUBLIC POLICY

### *Culture, Narrative, and Social Structure*

Social order is built on widely shared beliefs about how the world works and should work. These shared beliefs are the semiotic fabric in the social world, the configuration of meanings that acts as an ethical pedagogy enabling us to interact with one another inside our social groups and within the broader social structure of our time, which has been conceptualized as culture (Geertz 2003). We build this semiotic fabric by sharing stories (Fisher 1984; Loseke 2019). Thus, stories are a fundamental component of social interaction; they circulate in the social world, creating, reproducing, and perpetuating our widely shared beliefs about how the world works and should work—as we will see that the stories told in the Maine committee hearing regarding PAD do.

Narratives are ubiquitous in social life (Barthes 1966). We tell stories in our daily communication to make sense of the complexity and “buzzing confusion of human experience” (Loseke 2019:2; Bruner 1987): narrative is the primary form of human communication (Herman 2009).

Scholars have derived from this phenomenon the narrative paradigm, which is the view that humans give meaning to their actions through storytelling (Fisher 1984). We create culture through stories, through which we turn unique phenomena into generalizable categories (McCurdy, Spradley, and Shandy 2004). These generalizable categories become our shared beliefs about what the world is and should be like, and they are the symbolic codes (Alexander 1992) by which we make sense of our lived experience; they become part of our cultural toolkit (Swidler 1986). Symbolic codes, which define how we think things should be, are observable in the stories we tell in our daily communication, and they have corresponding emotion codes, which define how we think we should feel (Loseke 2019). Cultural narratives are deeply held beliefs that we simply “know” (Eagleton 2013:7). They contain taken-for-granted ideas that not only hide in plain sight (Zerubavel 2015) but also shape and affect our material lives. “Reality” is constructed in human communication (Burr 1995; Berger and Luckmann 1966) through narratives, which are culturally situated meaning-making tools (MacIntyre 2007; Bruner 1987) but flow across discourse types, communication media, and social contexts (Herman 2009), a migration that sometimes has unintended consequences (Mildorf 2002). In their flow, narratives can be differently formulated and evaluated (Gubrium and Holstein 2009); for example, institutions may control stories to fulfill the expectations they have about what the stories should do.

The narratives in the Maine committee hearing on PAD exemplify ways in which individuals transform varied and complex lived experience into simplified plots that draw from existing culturally shared beliefs and categories. These stories repeat links between symbolic codes and emotion codes, reflecting and simultaneously constructing the values in the arguments for and against the policy.

### *Culture and Emotions in Policy Narratives*

One site where we can systematically analyze ways in which broadly circulating cultural stories shape our material lives is discussions about the creation of public policy (Loseke 2019). However, narrative has not always received sufficient attention in the policy scholarship (Roe 1994; Filler 2001). What came to be called “policy science” (Tribe 1972) was born out of the concern of guiding political decision-making processes through the rapid industrial, technological, and postwar social changes in the mid-20th century (deLeon and Vogenbeck 2007). From the inception of policy science, there was an awareness of the interplay between values and facts in policy making. This awareness drove scholars who worked on developing such science to propose multidisciplinary and mixed-methods approaches focused on problem-solving (Lasswell 1951). However, critics argue that the field followed a narrower path and evolved into a study dominated by a positivist methodology and a rationalistic perspective geared toward obtaining generalizable and decontextualized findings (Fischer, Miller, and Sidney 2007).

Since the 1990s, scholars have been stressing that policy processes are strongly influenced by nonrational factors such as values and emotions (Putnam 1993), transmitted, for persuasion purposes, through storytelling (LaForge 2010). The power dynamics in and practical

configurations of the social structure, including what may be taken-for-granted institutional rituals that sometimes exclude dissenting voices or relevant empirical data or highlight specific views (C. Coleman 2016:2), have also been seen as relevant elements in policy decision-making. Under such a perspective, legislative debates are performative processes (Gottweis 2007; Hajer 2005) where persuasion skills, social credibility, and emotions are part of the “dramaturgy of policy settings” (Gottweis 2007:243). Scholars have drawn from linguistic theory to explore the pragmatic communicative function of speech and to conceptualize the speech in claims-making practices of social actors as forms of action (Austin 1962).

Within sociology, policy scholars have also explored the symbolic value of story lines in policy problems and their use to express shared beliefs and to define group membership (Stone 2002), as well as the relevance for decision-making of the types of talk used to define people, circumstances, and actions (Ehrlich 2003; Polletta 2006).

The debate about PAD to date has not been driven by facts and data, in part because of a dearth of data on the policy and on the social needs claims. It is driven more by a debate about value systems and is predominantly conducted through storytelling. The Maine committee hearing on PAD constitutes a performative setting guided by institutional rituals. In this setting, legislators and participants from the general public tell stories that appeal to emotions and reinforce values and beliefs, asserting group membership.

### *The Political Power of Self Stories*

In this paper, I adopt a narrative approach to policy analysis, and I specifically focus on personal stories. I build on the work of scholars who posit that legislative hearings—designed to gather information for committee members to shape legislation (Heitshusen 2015)—frequently become



what Zussman (2006) calls *autobiographical occasions*, as is the case of the hearing studied in this paper. Autobiographical occasions refer to “socially structured moments” (e.g., job interviews, classrooms, criminal confessions) when individuals are expected to describe, construct, regulate, and justify the self. The “self,” as Zussman defines it, “is not an entity, not a thing, but a story (or stories)” (2006:28).

Previous empirical researchers have theorized that policy has a narrative foundation and that policy makers are especially drawn to narratives in which they can adopt a central and heroic role, allowing them to connect the policies, public needs, and their own needs to assert jurisdictional authority and moral legitimacy (Jacobs and Sobieraj 2007). Others have shown how eyewitness accounts and stories about personal experiences in testimonies of legislative hearings are used by participants from the public as vehicles to persuade by sharing and validating cultural stories and themselves as speakers (Chock 1991). These analyses have in common the notion that people appeal to what others “know” to be true and present themselves as “trustworthy” individuals, to build what Shuman (2006) has conceptualized as the “storyability” (what does the story tell) and the “tellability” (who can tell the story) of their narratives.

In the Maine committee hearing on PAD, for instance, the organizer of the hearing speaks of her personal experience as a doctor and her father’s experience of death, validating her position as an expert through personal and professional knowledge. Most other legislators and members of the public who speak in favor of or in opposition to the policy also talk about their experience as giving them moral legitimacy to speak on the issue.

### *A Social Problems Perspective*

In this paper, I explore ways in which the self is “regulated” through the use of symbolic and emotion codes (Loseke 2019) in the personal stories of legislative testimonies. I hope to gain knowledge about worldviews and shared emotions of the broader social context, and I wish to show how appeals to emotions in stories are the primary means by which the normative points of stories are constructed (Loseke 2019; Elias [1969] 1994). I also want to demonstrate the possibilities of adopting an interpretive paradigm and a constructionist social problems approach when studying social phenomena in which the ambiguity of lived experience hides behind culturally polarizing opinions.

An underlying proposition in this analysis is that social problems are subjective phenomena that should not be understood as objective conditions that are harmful and measurable and affect a large number of members of a society, as positivistic views of social problems propose (Macionis 2007). Instead, I regard social problems as “a summary label” that encompasses moral, cognitive, and emotional evaluations of an issue that has been understood as concerning, widespread, harmful, wrong, and in need of a solution (Loseke 2019:50). Constructionists have demonstrated how some conditions broadly affecting people’s well-being may be taken for granted and not considered harmful, that the very concept of “harmful” may vary significantly from one social context to another, and that there is no single definition of “harm” that could be applied to all issues considered to be significant social problems (Best 2008). For example, discrimination can only be understood as the focal harmful factor of a social condition if negative attributions to that condition are not broadly taken-for-granted understandings about the world that are considered normal, as opposed to harmful. Compulsory able-bodiedness (McRuer 2006) is not a social condition that has as of yet been broadly

understood as inherently negative or harmful in and of itself. For the shared belief that something is a violation of human rights, we need to agree on a specific definition of what it means to be human and what constitutes a right (Golder 2019).

Constructionist scholars of social problems have theorized that social conditions become social problems through a process that they have called a *natural history* (Fuller and Myers 1941; Spector and Kitsuse 2001; Blumer 1971; Best 2008). They have argued that social conditions are typified and turned into generalizable categories (Ibarra and Kitsuse 1993) and that these typifications are shaped through symbolic attributions in claims-making processes (Spector and Kitsuse 2001). In these processes, public needs are defined and identified as requiring public solutions such as public policy. So an important step in analyzing policy is to identify how a need has been defined. Adopting a constructionist lens can help us determine, for example, if a need has been defined as being a “direct” or an “instrumental” need (Stone 2002:93). A direct need is one that will be specifically satisfied by the policy. An instrumental need is one that has been defined by the additional things the policy will allow us to do. Education is often viewed as an instrumental need, for example, because it may enable people to become better workers and informed citizens (Stone 2002). Arriving at an understanding of the way a need is defined can give us hints about broader cultural values. For example, students of modern moral philosophy (Rawls 2020) have argued that the predominant moral doctrine of the modern Western world has been utilitarianism, which does not favor the instrumental view of public needs. So understanding if the stories in a public hearing define an issue as a direct need or as an instrumental need can give us insight into broader social values.

In this analysis, I look at an advanced stage in the natural history of the construction of a social problem: the creation of public policy. The social problem leading to the discussion of

PAD policy was the proliferation of the medicalization of the dying process, which was seen as contrary to the value of having a good “quality of life.” The concern for the quality of life has been associated with the end of World War II and the civil rights movement, when values such as freedom and autonomy were incorporated as symbols of well-being, in addition to the possession of material goods (Boulton 2013). In the 1960s, the use of new life-sustaining medical technologies expanded greatly, and the need for PAD emerged from discussions on the quality of life and medical care choices at the end of life (Kutner 1969). Once PAD was broadly discussed in the public arena as a solution to the social problem of the artificial extension of life, a counternarrative then emerged espousing values related to the sanctity of life. More recently, the rights of vulnerable populations have been incorporated into the arguments against PAD. Thus, for opponents of the policy, PAD itself became the social problem to be addressed.

## DIMENSIONS OF THE PAD DEBATE

Constructionists have argued that contemporary changes in biosciences are affecting the sociopolitical management and the cultural understandings of death and the decaying human body (Kaufman and Morgan 2005), and I posit that the PAD debate is an empirical window into some of these cultural understandings. For example, analyzing the PAD debate can give us insight into possible future changes in the death system (Doka 2003)—defined as the combination of people, places, times, symbols, objects, and strategies related to the organization of death (e.g., warning, prediction, and prevention of death; care for the dying; disposal of the dead; social consolidation after death; help to make sense of death; and rulings regarding socially sanctioned killings). Constructionist research on PAD, however, is virtually nonexistent, in spite of the scholarly recognition of the value of using constructionist approaches in the study of

health and illness (Conrad and Leiter 2003) and the study of policy (Roe 1994). The bulk of the academic research on PAD done in the US has adopted either a positivistic or a critical lens, leading to findings that are mostly situated on one side of the issue or the other. What remains unexplored in the study of PAD is the cultural aspect of this public discussion, a gap that I try to address in this paper.

### *Transcending the Culture War*

Policy scholars have studied the success or failure of specific policy-making strategies for the legalization of PAD (Abernathy and Covich 2020; Harvey 2013), how the political battle in the US has affected PAD legislative efforts (Easterly 2019), and how efforts to legalize PAD have affected politics (Hilliard 2005). In the late 1990s, when the public debate on PAD took center stage after two Supreme Court opinions on PAD cases, academic research associated the defense of the policy with liberal Democratic ideology and the values of autonomy and choice, and opposition to the policy with conservative Republican ideology and religious values about the sanctity of life (Childress 1998). Various works also lumped PAD—along with abortion and the death penalty—as part of the battleground of a national “culture war,” where the moral reasoning behind decision-making (Glick and Hutchinson 2001) is ultimately tied to political party identification (Strate, Kiska, and Zalman 2001).

However, in this paper, I am more concerned with the broader cultural context inside which a political divide on a particular subject takes place, as well as with how social actors on each side of a political debate make use of specific sets of cultural stories to make sense of ideas, emotions, and actions. Public policy scholars concerned with mass politics in the US (Kahan and Braman 2006) have critiqued the thesis of the culture war as a tool to explain political

mobilization. They have argued that voters, more than being strongly committed to specific ideologies, are strongly committed to broader cultural values and that they entrust the analysis of policies that will materially affect their lives to those whom they assume are like-minded judges of empirical claims. In other words, instead of making the judgments themselves by analyzing complicated or simply inaccessible information, people trust their leaders' opinions and decisions (Kahan and Braman 2006:162). Drawing on this idea, in my analysis of the Maine committee hearing on PAD, my focus is not the relationship between opinions and political partisanship but the ways in which people draw from the pool of cultural stories circulating in social life about the subject to describe and make sense of their lived experience.

#### *Toward an Analysis of Circulating Beliefs and Emotions*

Some of the most recent studies on PAD have focused on changes over time in public opinion on the subject, arguing that the approval of the policy is increasing (Abernathy and Covich 2020). Other analyses have identified in this debate claims about what personal agency should look like at the end of life (Scoccia 2010; Pearlman et al. 2005). A 2019 US survey-based analysis measured the views of medical professionals about PAD and reported that most doctors saw the safeguards of the legislation in the US as sufficiently protective for vulnerable populations (Hetzler et al. 2019). A Canadian study of the early 2000s, broadly cited in the US, explored the negative impact of social exclusion on HIV patients who request to hasten their death (Lavery et al. 2001), a common concern about the limitations of the safeguards of the policy. Research done in European countries where euthanasia is legal situates inequality differently; for example, one study investigated social attitudes toward PAD in their relation to what the researchers conceived as a "death divide," where people of lower social status, material means, or education end up

deprived of what the scholars describe as the luxury of choosing PAD (Rietjens et al. 2012). All of these studies looked at beliefs and emotions regarding PAD, but all of them approach the subject from either a positivistic or a critical perspective and thus miss how some values and emotions transcend one side or the other of the debate. Disability scholars have largely explored cultural beliefs regarding this issue, yet they only critically explore the narratives in favor of PAD and do not explore the narratives against this policy. Such studies identify a prevalence of ableist beliefs that promote and perpetuate social inequalities and stigma, as well as institutional discrimination against people with disabilities in the narratives that promote PAD (D. Coleman 2010). In my analysis, I also found elements in the narratives against PAD that are consistent with ableist views.

### *Defining Public Needs*

A contextual issue that has recurrently been addressed in research on PAD is the structure of the US health system, specifically in relation to the care of dying patients. Some scholars have argued that in the US, efforts for and conversations about legislative change should not be about PAD but about improving the health care system (Foley and Hendin 2004), while others have argued that PAD should be systematically and carefully incorporated into the end-of-life care system as one more choice for patients in hospice (Campbell and Black 2014). US doctors involved in pro-PAD advocacy point to an urgent social need for the avoidance of pain and loss of control of bodily functions as well as for the promotion of autonomy for the terminally ill (Quill, Black, and Block 2016). Comparative analyses of PAD around the world describe a US medical system where hospice facilities are scarce, and doctors are reluctant to make the shift in their treatment from aggressive curative treatment to palliative treatment (Scherer and Simon

1999). As with the works discussed in the previous subsection, all this research is reporting either found “truths” or power dynamics, but none of it is looking at the meaning-making process constructing the narratives of the claims. Among the few works with a more constructionist perspective, there is a Canadian study that identifies the tropes of “suffering” and “autonomy” as central to the right-to-die movement, as well as issues of excessive medical treatment at the end of life (Karsoho et al. 2016), but the study does not explore the countermovement at all.

In the Maine committee hearing, speakers make reference in their stories to problems with the structure of the medical system and practitioners’ decision-making, but to understand how these stories work toward the construction of public needs, it helps to identify critiques that are common to both sides and to observe the broader value system from which the critiques draw their logic.

### *Constructionist Concepts*

In the Maine committee hearing, the different narratives conceptualize the issue of PAD as one about either autonomy or inequality, and depending on the view, the meanings attached to the symbolic codes of choice and dignity vary. In this analysis, I hope to gain knowledge about how these definitions and codes have come to be possible. The constructionist concepts of *medicalization*, *the good death*, and *the economization of death* help to explain some of these meanings, for these meanings appear to draw from logical modalities (Foucault 2012) that have been identified in the contemporary institution of medicine, an institution that occupies a predominant part of the contextual background of the PAD discussion.



## MEDICALIZATION

Medicalization is a contested concept that dates back to early constructionist and critical approaches to the study of health and illness (Illich 1976; Zola 1972; Foucault 2012; Szasz 1970; Conrad and Schneider 1992), often explored in relation to psychiatric medicine and understandings of disability and used to problematize issues such as preventive medicine (Verweij 1999). The concept has been used to describe a growing tendency in Western societies to define various human experiences, conditions, and actions that were previously considered common in human life as medical problems in need of medical treatment (Conrad and Leiter 2003; Conrad 2007; Conrad and Schneider 1980, 1992; Halfmann 2012; Ballard and Elston 2005). Critics of the traditional use of the concept of medicalization equate it to the idea of pathologization and argue that reductive assumptions limit what qualifies as “medical treatment” (Sholl 2017). The options discussed on both sides of the debate on PAD propose a medicalization of death: while PAD may be viewed as the avoidance of medical technology that prolongs life without improving the quality of life, it still implies medical technology in the form of lethal pharmaceuticals to circumvent pain and lack of bodily control by dying, and it also implies the approval of the medical institution. Scholars who have explored this view have conceptualized PAD as a form of medicalization of suicide (Salem 1999). And PAD opponents’ promotion of hospice instead of PAD implies utilizing the medical system and its professional help and care practices in the process of death.

## THE GOOD DEATH

Scholars have argued that, in the 20th century, an institutionalized ideology of the good death has dominated the management and politics of the care for the dying (Hart, Sainsbury, and Short

1998:74). The institutionalized ideology of the good death is described as having emerged from people's need to gain control over their dying processes in reaction to the care being received in hospitals (Hart et al. 1998:74) and having been strengthened by notions drawn from the work of the American psychiatrist and death expert Kübler-Ross (1969). Though not without criticism (Kastenbaum 1998; Stroebe, Schut, and Boerner 2017), Kübler-Ross's theoretical model, which proposed that dying patients go through five emotional stages of grief—denial, anger, bargaining, depression, and acceptance—was broadly disseminated through the education of nurses (Germain 1980). Among care professionals, Kübler-Ross's model became the normative standard to determine what the role of the terminally ill patient should be, and the expectations of that standard became restraining for the choices of people in their dying process (Hunt 1994). Noncompliant patients were thus viewed as deviant (Germain 1980), and critics argue that Kübler-Ross's theoretical model is less related to the process of dying itself than to the adaptation of dying persons to the institutional contexts where their process takes place (Charmaz 1980). Both the hospice and palliative care movement and the right-to-die movement—each embedded in different value systems: the hospice and palliative movement in the religious tradition, and the right-to-die movement in the humanist philosophical tradition (Maddocks 1996)—have been said to challenge the institutional narrative of the good death (Hart et al. 1998). However, the narratives in the Maine committee hearing show that both sides talk about the good death in relation to one's acceptance of dying and that both make appeals to culturally shared and taken-for-granted notions about what it means to suffer (Cassell 1998). Proponents of PAD emphasize the necessity of controlling one's own body, and opponents of PAD emphasize the right to be loved, accepted, and assisted with the needs of one's body.

## THE ECONOMIZATION OF DEATH

The economization of death is the name that medical researchers have given to what can be understood as an ethical logic or set of values dominating public opinion in the US regarding end-of-life expectations (Kübler-Ross 1969; Shmerling et al. 1988; Fox and Swazey 2008).

Scholars have argued that the economization-of-dying values are a cultural by-product of the bioethical movement of the 1950s and '60s, which was born in response to the emergence of new medical-care technologies, and which sought to protect patients' rights and avoid medical paternalism, or "medicine's overambition" (Fox and Swazey 2008:116). The medical field adopted a logic of that "presents a rationale to economize dying: restrain, adjust, and appropriate medical interventions, based on evaluations of their morality, cost, and utility" (Livne 2019:13). This imperative for economization was internalized by doctors who became compelled to convince patients that less invasive procedures were better. A consequence of this logic was that doctors began to turn to patients as the ethical compass for decision-making at the end of life and adopted the patient-autonomy approach as their dominant orientation (Livne 2019; Fox and Swazey 2008). This shift in the patient-doctor relationship transformed the characteristics of what Parsons (1975) called the "sick role"<sup>2</sup> by generating increasing expectations of patients' participation in the decision-making process of illness and the medical treatment. This ethical logic was represented by the story of fully autonomous patients resisting clinicians who wish to prolong their lives, which synthesized complex ideas and feelings about this subject. However, Livne (2019), who examined clinical records of cases brought to the ethical committee in a California hospital, argues that even though there may still be a dominant preference for

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<sup>2</sup> Parsons theorized that an ill person had two rights and two responsibilities: the rights not to be blamed for the illness and to be relieved of their normal responsibilities (the power of the medical excuse); and the responsibilities to get better and seek proper treatment for their condition.

economizing dying, this preference is declining. The autonomous patient is one of the formula characters in the stories of the Maine committee hearing on both sides of the debate. The idea that patients want their choices respected is present in all the narratives, and the resistance to the prolongation of life is the centerpiece of the stories in favor of PAD.

I build on previous studies on PAD, such as the ones discussed in this section, and draw the concepts I just defined from constructionist literature on health and illness to explore the cultural and symbolic dimension of the stories on PAD at the 2019 Maine committee hearing.

## METHODS

### *Site*

The documents (written testimonies and audio recording) analyzed in this paper correspond to the public hearing of the Joint Standing Committee on Health and Human Services on the bill LD 1313, titled “An Act To Enact the Maine Death with Dignity Act” (Maine State Legislature 2019a), during the 129th Maine Legislature’s First Regular Session of 2019, December 5, 2018–June 20, 2019 (State of Maine 2019), in preparation for the committee’s final work session on the bill on May 1, 2019. The hearing took place on April 10, 2019. Speaking at the hearing and/or submitting written testimonies were 10 members of the committee and a few other Maine legislators, along with members of the medical profession (nurses, doctors, pharmacists), lawyers, veterans, and other Maine constituents (most of whom identified as family members of people who had terminal illnesses), and a few out-of-state advocates (both secular and religious).

After the hearing, the committee met and deliberated, recommending passage after adding a number of amendments. The Maine House of Representatives passed the bill on June 3, 2019, and the Maine Senate passed it on June 4, 2019. After the governor signed the final bill

(Maine State Legislature 2019b), it became public law on June 12, 2019. The committee members who organized and moderated the hearing are both physicians in favor of the bill and had been part of the legislative discussions on PAD since at least 2015. The legislative history archives on PAD in Maine date to 1992 (Maine State Legislature 2021b).

The way in which the organizers interact with the participants and the presence of only one expert guest speaker, whose position favors the legalization of PAD, suggest that the organizers were not impartial. The organizers were the sponsors of the PAD legislation and clearly were in favor of its passage. When they address opponents, they mostly ask rhetorical or leading questions, or they ask them to check their facts or to follow the rules; only proponents seem to be asked questions seeking further information about the content of their testimonies. For example, the guest speaker in favor of PAD who self-identifies as an expert is asked the following question requesting elaboration of details regarding the PAD process: “What if the condition is controllable—the definition of ‘terminal disease’ does not require that the condition be uncontrollable—how would you answer that?” In contrast, an opponent who makes an argument about a possible slippery-slope effect of the law is asked, “Are you aware of ... any other state in the United States that have had these laws—say, Oregon for 20 years—that have expanded their eligibility? You talked about expanding eligibility.” The organizer follows that question with the comment, “Okay, I believe that they have not, so, just to let you know...” This bias on the part of the organizers potentially limited the extent to which opponents of PAD could express their concerns or make their claims. It also meant that during the hearing, the organizers attempted to sidetrack or divert opponents’ claims into a narrative that they preferred. Thus, in my analysis, I paid careful attention to PAD opponents’ narratives, particularly the unmediated written testimonies, to separate their narratives from the organizers’ mediation.

### *Data Selection and Classification*

The data in this study have been drawn from the public archive of the Legislature of Maine, available at this institution's website: 106 one- to two-page PDF files and an audio recording of the five and a half hours of the hearing of the Joint Standing Committee on Health and Human Services (Maine State Legislature 2021a). The testimonies presented orally during the hearing totaled 68 (37 testimonies in favor, 30 against, and 1 neither in favor nor against), including 30 that had corresponding written testimony; 76 additional written testimonies were not presented at the hearing. Most speakers at the hearing read their testimonies verbatim. I transcribed the spoken testimonies that were not available in the written archives. Together, the hearing and the written testimonies constitute the information that legislators would have had access to in their decision-making process.

The organizers of the hearing intended to have consecutive groups of five testimonies in support of the bill, followed by five testimonies of opponents and then five neither in favor nor against. However, the order in which the signed-up participants were actually able to speak ended up being more random in practice than the organizers had expected as per their announcement. All the names have been replaced with pseudonyms, even though they come from publicly available documents.

A limitation of the data selection is that because the data consist of existing documents (written testimonies and the recording of a hearing), they do not allow for determination of the demographic characteristics of the individuals involved. The possibility of drawing conclusions based on gender, education, class, race, or ethnicity differences is thus excluded from this analysis. Further research may be necessary to explore to what extent the exclusion of the voices

of “marginalized and discredited social groups” (Livne 2019:114) is a determining factor in the patient-autonomy narrative.

For this narrative analysis, I began with a close reading of all written documents and listened to the five and a half hours of the hearing three times while taking notes to get a sense of the theme patterns in the discussion. I initiated a process of categorization to classify general themes and patterns (Zerubavel 2015). I treated the narratives as literary pieces, by classifying character types, plots, and settings (Loseke 2019). Recurring rounds of classifications followed to group and analyze the types of characters and the symbolic attributions of motives given to their thoughts, emotions, actions, physical appearance, and settings in order to appeal to audiences (Harris 2010).

I focused on those symbolic attributions that seemingly appeal to broadly accepted feeling rules (Hochschild 1979) and belief systems (Swidler 1986) about health and illness. To interpret the plots, and the moral representations in them, I observed the actions and interactions of characters, the sequence of events, the evaluations of other story elements such as places and times, and the descriptions of emotions. The categories of “choice,” “dignity,” and “do no harm” seemed to be the normative principles behind the feeling rules and moral duties attributed to the health professionals and patients in the patterns of the predominant formula stories shared through the personal narratives (Berger 1997). I thus focused my analysis on these two characters and on the stories constructed around them.

## DATA ANALYSIS

The data samples in this analysis come from the testimonies of state legislative representatives, advocacy group leaders, and professionals and individuals who share stories about personal

experiences and experiences of people they know to express their views and emotions regarding the PAD policy and the bill that was to be approved in Maine soon after this hearing. Some address the need for and possible benefits of legalizing PAD. Others emphasize the urgency of preventing its legalization and the potential social harm that the policy could generate. There are formulaic plots that appear and reappear in the testimonies that seem to describe core cultural beliefs and emotions that all participants share, one of which is that “doctors should be caring people.” But because these stories are tools to make claims about social needs and risks, given the context in which they appear, they also bring formulaic plots to the conversation. In these plots, the competing interests are made clear; after all, the purpose of this hearing is to determine whether or not it is a good idea to legalize PAD. In the stories about the relationship between doctors and patients and at the intersection of these two characters, I found two recurring patterns of events: a “miserable death” that could have been avoided in the claims of PAD proponents; and the irreparable mistake of the “wrong solution” in the claims of PAD opponents.

### *PAD Proponents: The Story of the Miserable Death*

As a dramatic narrative (Fisher 1984), the “miserable death” helps construct the public need, an essential step in policy making (Stone 2002). This story proposes that preventing bad deaths is socially necessary and that a policy on PAD will fulfill this need. Consider the plot in the story of Sally, who speaks of her experience as a nurse:

I have held the hands of patients and family as they are ready to, and in the process of dying. They do not want to suffer as they wait for the body’s systems to finally let go. After sitting by the bed of my 55-year-old brother as he battled and died horribly from



pancreatic cancer, I found a more personal reason to advocate for the option for death with dignity. I wish he had that choice. I would like that choice. (Sally)

Sally's story summarizes the simplest form of the plot of the miserable death: people can sometimes fall victim to terrible illness that makes their bodies stop working, making them suffer greatly before death. Sally's story also demonstrates the two points of view of narrators in the testimonies: eyewitnesses of strangers' deaths (often professional health providers) and vicarious victims of the agony of loved ones (very few narrators are also patients themselves). Sally's story reproduces some of the cultural values and feeling rules about death, including that dying young is sad: narrators almost never say the age of an elderly parent who died, whereas children's and younger adults' ages are always mentioned. Cancer is a symbolic code for physical agony, and it is the most frequent illness mentioned in these stories.

There are also feeling rules about fearing death, and PAD supporters acknowledge these rules by often referring to people's readiness for death in these extreme circumstances. The fear of suffering for PAD supporters is greater than the fear of death. It is the moral duty of families to be united in difficult circumstances such as illness. Patients and family must feel love for one another, and their relations must be uncomplicated by negative emotions. The moral duty of those who understand the suffering of horrible deaths is to help people in agony to choose their own moment and time to die. No amount of medical help or technology can prevent the agony when the time comes, and loved ones must watch in despair, when the possibility of having a good death could be so simple, as Marianne puts it: "If my fate is the same as my parents, why not let me choose to listen to music on my deck with a glass of chardonnay in one hand and the hand of the one I love in the other and drift off peacefully."

In the next excerpt, Myriam, an experienced nurse, typifies the miserable death as a long and inevitable fate of many people within the health care system, in spite of end-of-life services offered:

As a registered nurse for 25 years, I have worked with many patients who are delivered the unthinkable—the diagnosis of a terminal illness—and begin a journey through the healthcare system, participating in what might be available for treatment, including palliative care and hospice and, finally, dying. Sometimes, their journey is peaceful but often it is horrific in spite of all the services, the medication, and the expert care we have to offer. (Myriam)

By participating in the plots (Zussman 2006; Jacobs and Sobieraj 2007), narrators signify their emotional involvement, their cognitive soundness, and their moral authority (Shuman 2006) and place themselves as living tools to prove, appeal, and argue (Chock 1991) what it is to be human. All the narratives supporting PAD help to build the restricted story line of the miserable death, and each adds to the theme of the patient-doctor relationship, in which patients must seek autonomy and demand to have a “choice,” an alternative to misery, which stands in opposition to their dignity. Tracy, a doctor, asserts her connection to the concerns of her constituents (Jacobs and Sobieraj 2007) by saying, “This is a difficult issue to spend the day with, but for many of the people you will hear from today [this] is what they are confronting now and daily.” She then adds,

I diagnosed and treated a 36-year-old man from Kittery with Amyotrophic Lateral Sclerosis (ALS). He told me when he couldn't get out of bed on his own, he would see no point in living longer. When his hospice nurse called me one day to tell me he couldn't get out of bed on his own, I went to his house to see him. He cried to me that this was his life, and he wanted his own death to honor his life. Using this law would have allowed that honor and freedom with humanity. (Tracy)

Freedom and dignity are key symbolic codes of human rights in Tracy's quote. Mobility is equated to a fundamental aspect of living: without mobility, life ceases to be worth living, which expresses a taken-for-granted view of normalcy, consistent with broadly shared values and emotions regarding disabilities (D. Coleman 2010).

#### VICTIMS, VILLAINS, AND HEROES

Victims in the stories of PAD supporters are people with terminal illnesses who suffer, endure, love, and resign themselves to their fate. Villains are opponents of PAD who are defined by their indifference. Heroes are medical professionals and sometimes family members who understand and help the victims. Family members are sometimes second-order victims and sometimes heroes who love and suffer with victims but fight for the rights of all. The moral obligations of the three formula characters of the miserable death formula story are present in this narrative. The victim, a powerless patient who dies undignified by impairment and pain, should rather have chosen death. The heroes, understanding medical professionals who try their best and give their blessing, should have helped to end the person's life if they had been allowed to. The loving family members are forced to watch and to suffer along with victims and then assume the

obligation of heroic advocacy. The villains in these stories are abstract forces delaying PAD legislation. A lack of compassion that allows unnecessary suffering is implied, but there are very few references to concrete villains: illness mostly takes the blame. James describes the experience of his wife, Kate, a cancer patient for 27 years who died at the age of 58:

Rather than taking on the emotional and physical toll of yet another treatment, she decided to spend her final time preparing for the eventuality she anticipated for a long time. With full cognizance and confidence, and the blessing of all of her doctors, she agreed to enter hospice. At that point she decided she was ready to die. ... There was no turning back, yet we endured an extended period of time where Kate became less functioning, needed extensive morphine for pain medication and assistance with absolutely everything. ... She was lingering and waiting to die. Why did Kate need to go through this? (James)

In James's description, Kate had been a good patient who should have had a good death. She had arrived at resignation and was at peace but was forced to "linger" past what would have been the right time for a good death. Similarly, Kyle describes her father's agony:

My father ... die[d] after a long period of recovery from prostate cancer. For years his survival was a good one—and rewarding for he and those around him. But in the last two to three weeks, it was a continuous and painful end. For some time near that end, it was I who was charged with administering the morphine that kept him somewhat pain free in the coma that enveloped him near the end. And it was me who decided that, although I

knew that increasing that dose would likely result in a quicker exit from his dying process, I couldn't do it. I didn't do it—but have been haunted by the memory that as he lay there in home hospice care, I let him suffer. (Kyle)

Both Kyle and James had to endure the pain of their loved ones, victims of illness. They both went on to fight for the choice their family members were not granted. Kyle speaks of the guilt she feels over her unfulfilled moral duty; she also had no choice. Preventing her from doing the right thing was the lack of a PAD law.

In the descriptions of the characters in these stories, political partisanship rarely appears, whether in favor of PAD or against. When it does, however, it is used to demystify the divide on this issue. In the stories in favor of PAD, for example, the assumption is that everyone understands the need for PAD on a deep emotional level, regardless of partisanship. The following story, however, does acknowledge the culture war and the possibility of this issue being part of it:

I seem to have the recessive liberal gene in a very conservative family; both of my brothers are staunch Republicans and they want to be able to die with dignity too. Litchfield is a very conservative town, yet I'd say 90-percent of the people I've spoken with in town support this bill. I am way left of most voters, ... yet one man who opposes me on every political issue also supports this bill. He came up to me and said—"I never agree with you on anything but I'm definitely for this." Then with tears in his eyes added, "my mother called me last night, she has stage 4 breast cancer and she wanted to know what state she needed to move to have a death with dignity option." (Marianne)

In Marianne's story, PAD is presented as a unifying force, bringing people from different political camps together, because anyone can be subject to the experience of a miserable death. Love and compassion unite all those who have witnessed the suffering of a loved one. More specifically, Republicans do not necessarily have to be the villains who prevent the solution to the miserable death, because they too understand the benefits the law can have for them in their personal lives.

#### THE MEDICAL SETTING AS THE SCENE FOR THE PLOT OF A BROKEN SYSTEM

Consider the description of the hospital setting in the following sample:

Once they [patients] are in the medical arena and outside of their homes, there are many obligations that are borne out of protocols or legal constructs where providers practice in a manner that is not consistent with dignified end of life care. I have seen many examples of this through my career. (Myriam)

PAD is a medical practice that could be understood as a "legal construct," which would necessarily generate "obligations" and "protocols" in which the same providers who "practice in a manner that is not consistent with dignified end of life care" would become the decision-makers. This story continues as follow:

I remember a man who had a large parotid, or salivary gland, tumor which was growing larger despite chemotherapy and radiation. Due to the location of the parotid gland at the

angle of the jaw—as it grew it became more difficult for him to speak, breathe and swallow. The growth of the tumor was rapid. His mental state was understandably depressed and fearful, however, he remained completely competent. His family was fearful for him as well. It was known to all that he would not survive through another month. Because of the rapid growth he declined quickly and even with hospice care he had multiple trips to the ER to help manage the side effects of this growing tumor. He spoke candidly about wanting to be able to end his own suffering and be at home. He was facing the inevitability of death in such a stark manner that he was able to speak so openly about it with us as providers. He would ask if there was anything that we could do to help him. (Myriam)

Consider the attribution of motives in the second half of the text: (1) Why does the patient act and feel the way he does? (2) Why does his family react and feel the way they do? (3) Why does he plead to his health providers? (4) Why does he want to go home? The symbolic references in this story—to illness and impairment, to incurability, to the availability of medical technology, to emotional weakness but cognitive strength, to figures of authority and place value—illustrate key issues of the PAD debate. Symbolic and emotion codes are interconnected to establish moral obligations: patients must seek treatment first; while families may be scared, they ought to be strong and let their loved ones decide; patients must remain in control and seek help from doctors; and dying at home should be socially valued.

In sum, the story of the miserable death revolves around empowering victims who need the protection of the law to be able to retain personal agency at the end of life. Most personal stories told by proponents of PAD describe how the lack of choices at the end of life within the

medical system threatened people's dignity and freedom. Next, I discuss the narratives of PAD opponents, whose focus is on PAD being the wrong solution.

### *PAD Opponents: The Wrong Solution*

In the counternarrative in this hearing, the stories contest the proposed bill allowing PAD in a number of ways. Just as in the miserable death story, there is a confluence of formula stories in these narratives that together work toward a shared opinion: PAD is the wrong solution to the problem of a bad death; its irreparable consequences mean that it is necessary to find all possible alternatives:

I have a friend who was diagnosed with terminal cancer and was given just a few months to live. She went ahead and did the chemo treatments because she had family that depended on her. It has been ten years. She is alive and well and full of life. What if she had lost hope and taken the medication for assisted suicide? How devastated her family would have been! (Beth, legislator)

Beth's story shows a core argument of the narrative against PAD: PAD removes hope. The physical conditions of Beth's friend are not described, only her moral duty to survive for her family and her hope for survival. Her family's emotions, however, do allude to the idea that PAD would have been the wrong solution. She would have caused great pain in vain. There are no descriptions about cancer treatment's costs or side effects, logistical complications with caretakers, or personal status. All we are told is that dying would have been the wrong option. Beth's friend had hope, but she also had no choice: her family obligations prevailed. An



underlying issue here is the accuracy of prognosis, an issue that has been discussed in the literature on PAD since early in the national debate (Dinwiddie 1992) and that is frequently discussed regarding end-of-life care (Christakis and Lamont 2000). However, the issue is complicated for it involves a discussion not only about the limits of medical knowledge but also about the role of emotions in the patient-physician relationship. PAD also does not guarantee dignity or that a person's death will not be bad, a concern that Ray, a pharmacist whose story I explore later in the text, demands of the legislators evaluating a bill that he claims does not even plan for adequate medical response to crisis:

What happens when seizures occur? ... Where is the dignity if there are not health care providers there with the adjuvant and supportive medications often needed to really make sure that the last moments of life truly are dignified? (Ray)

In other testimonies against PAD, youths, veterans, and people in contact with the law who may not be terminally ill are also defined as potential victims of a PAD policy, if not as direct users of the medical practice, then as emotional casualties of a policy that normalizes suicide. This isolates the symbol of choice from the difficult burden of the "death sentence" of a terminal illness and pairs it with potentially curable mental illness or even just social isolation. In the following example, Chuck argues that PAD eliminates people's choices and that he, as a police officer, has been able to bring people back from feeling the trap of hopelessness, preventing them from making the wrong choice:

I just wanted to say before I tell you about what this person's testimony is that I have been in law enforcement for 32 years, and 25 years on patrol, and I've witnessed people who wanted to commit suicide, they were very depressed and wanted to end it, and I have talked them out of it. (Chuck)

Aside from removing people's hope and choices, the legislation is also characterized as being deceiving, as can be seen in Dan's story:

As a pharmacist, I have spent my career trying to help cure. ... Having lost many family members to cancer or other chronic illness, I saw firsthand that hospice care was not only available, but that it was extremely effective at supportive end of life care. And by effective, I mean that I know for a fact that there is no single dose of drug that will easily end someone's suffering. Even when manufacturing the death of a condemned inmate in a prison, many times it just doesn't go quietly or to plan, and at the very least dignity is not a word I would associate with the process. So families at home, without supportive hospice type care, have no idea what can go wrong with self-administration of a suicide dosage. ... Most folks have no idea what is really possible to go wrong, and they are not trained or prepared to be aware of the consequences. Although on the flip side this bill would prevent the prescriber from being present, so at least we will spare them from the potential ways the process can go sideways. (Dan)

Here, Dan characterizes the legislation as one that promises a good death that it cannot guarantee and characterizes hospice as the alternative, the right solution. In Dan's narrative, families,

because of ignorance or naiveté, can inadvertently be complicit in the villainous act of effectively provoking the very “miserable death” that they may be trying to avoid; doctors, on the other hand, win with this legislation: they are the only winners in this story, for they will be protected by the law in the event that anything goes wrong.

#### HEROES, VILLAINS, VICTIMS, AND FOOLS

The characters in the samples from the “wrong solution” story can be divided into four categories, where heroes, victims, and villains are the main ones, just as in the miserable death story, but where fools are another salient character. In Beth’s seemingly uncomplicated narrative, the value system that divides all characters is symbolized by Beth’s friend alone. Beth’s friend, a cancer survivor, is a hero, who could have remained a victim or been a fool who turned into a villain. Her transformation process was made possible by hope, which is the centerpiece of “heroism.” Beth’s short narrative also contains the symbols of “medical error,” the source of foolishness, and “family suffering,” a central concern of victimhood.

Through hope, heroes help victims recover joy. Anaïs, who works with elders “who live alone and crave company,” defines joy as the missing piece in the victimhood of patients:

I began spending time with them, listening to their stories, reading them poetry, preparing meals for them. ... I also make sure that they take their medication on time, that they stay clean. ... They are happy with little things. They crave a kind word or a gentle touch.

Something different to eat. A lovely picture, a song. (Anaïs)

Anaïs's claim is about a loss of social cohesion resulting in the abandonment of elders by their families. Fear of death, and the possible difficulties of the process of death, is not a worry. In Anaïs's story, people consider PAD only when they are victims of a lack of compassion from others and a lack of social services. Anaïs's clients illustrate the alternative to being such a victim:

They know that when they go to sleep at night they might not wake up the next morning, and for them, that only makes every moment more precious. They are not, obviously, in perfect health. They are very old. They have access to a nurse, or, if needed, a doctor—several doctors, in fact. But they would never dream of asking a doctor, or anybody, to kill them. (Anaïs)

Heroes can detect fools who cannot see the true villains, represented by the medical industry and insurance companies. A lawyer describes issues related to what scholars have called the death divide (Rietjens et al. 2012):

My legal work deals primarily with helping low income individuals get the medical treatment they need and want. ... I don't question the good intent of those who support the bill. But their good intent does not protect people from the deadly content of their proposal. (Chris)

Joy shares a story she has read that shows both the transit of cultural stories through social levels and the transferability and impact of personal stories. Her story is a clear example of

how insurance companies and the medical “industry” are characterized as not trustworthy and as dangerous social actors in relation to this legislation: “Stephanie Packer, from California, has a terminal illness. Her insurance company denied life-sustaining treatments, but would cover the \$1.20 co-pay for the life-ending drugs” (Joy).

In the “wrong solution” story, doctors have the duty to be heroes. Tim describes how he has fulfilled his duty:

I’m a board-certified internist and cardiologist from Beverly, Massachusetts. I practiced over 44 years including 35 years as the director of a long-term care facility mostly tending to dying patients, but I never once wrote a prescription for a lethal dose of medicine with the intent to have a person kill himself. (Tim)

This story contains two claims. The first is often discussed in legal debates on PAD: that the medical practice of helping patients hasten their death is already well established among medical professionals, whether it is legal or not (Albany Law School 2018). The second claim is that PAD operates against the moral integrity of doctors and that it harms the medical profession and the patient-doctor relationship of trust. Ryan, a doctor, describes medical education, alluding to the Hippocratic Oath, a commonly cited text in these debates:

We as physicians are taught to preserve life, to protect and defend it. ... But not to kill our patients. To give an individual physician, and the medical profession a new role as “life ender” will forever break the sacred bond of trust between doctor and patient.  
(Ryan)

Ryan elaborates on the vulnerability of victims of terminal illness, noting the shared values and emotions that correspond to the notion of a culturally compulsory able-bodiedness that disability scholars and activists point to (McRuer 2006):

I have had the unpleasant duty many times over the years to tell a patient that they have a terminal illness. While many of them receive the news stoically and almost none of them develop clinical depression or other mental illnesses which would exclude them from the ability to receive physician-assisted suicide services were this bill to pass; no one ever really sees the world in the same way again. I fear this sense of becoming a burden to their loved ones would cloud the judgement of some to the point of driving them to end their life prematurely. (Ryan)

#### A BROKEN NATION: SAFE INSTITUTIONS

Although hospice is talked about frequently in these narratives, the true setting of this story is a broken nation, where the traditional values of family and the medical institution are eroding and morality is deteriorating and where people need to recover hope, not promote suicide. Marilyn self-identifies as a Maine constituent and a caretaker of veterans:

In the 18 years I spent caring for our veterans, many hours were spent listening to gut wrenching stories. ... They came home, after months or years away, to find “home” had greatly changed. In addition to suffering this culture shock, they have physical disabilities such as burns and amputations, PTSD and night terrors. Do you know that an average of

20 veterans commit suicide every single day? To say it is OK for a physician to assist in suicide is ludicrous; we already have a national crisis without the doctor's help!

(Marilyn)

In such a national context, legalizing PAD would cause (and has caused) great harm; it would be a step toward giving power to the corrupt, as Joy argued by sharing the story of the insurance company offering PAD to patients. Also, everyone could be declared eligible for PAD, a concern voiced by Lesley:

Proponents of this law paint a rosy picture of doctor prescribed suicide. The reality of this law, as it has been put into practice in other states, paints a different picture. ...

According to the wording of this bill, a "terminal illness" can be anything that is incurable. ... How many people do you know personally who would die if they didn't take their insulin or breathing medication? I know many. My job as a nurse is to advocate for all of my patients. (Lesley)

Lesley is also concerned with her moral duty as a health provider. Her story also brings up the case of diabetes, which is a recurrent concern in other testimonies.

Another part of the condition of a broken society is the prevailing capitalist values, which have eroded the unity of family:

I'm a firm believer that when Sean [*referring to himself in third person*] turns 68 years old and he is not able to provide taxes or family matters or what have you, I'm a firm

believer in my lifetime, making my kids' lifetime, they are gonna say, alright, it's time to pull the plug because he is no longer needed and a benefit to society. (Sean)

Dan, who in an earlier story questioned the system for protecting doctors, also asks, "Are relatives that are heirs to an estate allowed to be in the room?" According to PAD opponents, PAD would allow corruption at many levels of society: if heirs can be present at the moment of death, and doctors can choose their friends to corroborate that patients are eligible, then patients would not be safe with anyone. These dangers are described for the most part as unintended consequences, but capitalist values represent a terrain of high risk for such casualties, perhaps one that insurance companies would take advantage of given the structure of the US health system and the logic of the economization of death.

In sum, the story of the wrong solution revolves around disempowering villains who would be allowed by the proposed PAD law to abuse their power and coerce people to commit suicide. Most personal stories told by opponents of PAD describe a society where there is a deterioration of values and lack of compassion and care for vulnerable people, particularly in their dying moments.

## DISCUSSION

### *Sensemaking, Emotions, and Storytelling*

This analysis shows how reliant social communication is on storytelling, how significant the use of personal stories is in public life, and how stories and collective emotions participate in regulation of social life and the organization of social structure. Humans use stories as an essential tool for sensemaking because stories' symbolic dimension helps us explain, interpret,



and classify the complexity of human experience and build our personal and group identity. We draw from broadly circulating cultural stories to delineate the characters, actions, and settings of our personal stories, which we use to synthesize and symbolize the values and emotions we attach to our lived experience. In turn, our daily communication in social life incorporates our personal stories to the stories about social phenomena that circulate at the cultural level.

### *Culture and Policy*

Exploring the deployment of stories in a policy-making process helps us gain knowledge about the interplay between social culture and social structure. For instance, a significant finding from the data explored in this paper is that both sets of testimonies in the Maine committee hearing, which stand in opposition to each other and seek contesting results, also share prevalent cultural beliefs about health, death, impairment, the health care system, the medical institution, and the relationship between patients and doctors. The narratives in these testimonies draw from and contribute to a common cultural toolkit, and they show the values and emotions of the social context in which they take place. These stories in particular make visible currently prevalent and taken-for-granted understandings about health and illness and the institution of medicine in the contemporary United States.

The first shared belief I observed in these stories is that processes of death from terminal illness must be overseen by the medical institution, despite the critiques that the narratives make of the medical system and of doctors. Underlying this belief about the dying process are shared emotions of mistrust and dissatisfaction toward the institution of medicine in the US, which is viewed as a system that does not always make available the services that people require. Both sets of testimonies deploy stories that function as speech acts, setting cultural norms for social

interaction. For example, the stories establish that medical professionals are the appropriate source of help for people at the end of life but also that people ought to have reservations about the knowledge, capacity, and/or the intentions of doctors and must protect themselves from what scholars have conceptualized as medical paternalism (Livne 2019; Fox and Swazey 2008). The second cultural belief shared by proponents and opponents of PAD alike is that impairment is a factor that devalues life and that it is natural for people who become physically impaired to want to die. Some propose honoring such a wish and legalizing a medical tool to hasten death, while others claim that the existence of such a tool would be a cruel temptation for people in despair; but the testimonies on both sides speak of impairment and lack of bodily control with unquestioned rejection. The third cultural understanding shared by both sides of the debate in these stories is that suffering at the end of life must be avoided, whether suffering refers to physical or emotional pain.

### *Stories and Claims-Making*

Part of the function of stories as speech acts in these sets of testimonies is to make claims about the social problem behind the policy discussion on PAD. Stories in these testimonies make associations between specific symbolic and emotion codes. For example, proponents of PAD frequently feature the symbolic code of cancer as an appeal for empathy. The experience of this disease—a disease that is broadly associated with lethality, acute degrees of physical pain, loss of bodily control, and social dependency in its advanced stages—synthesizes factors that are used to symbolize indignity and suffering in these stories. Cancer is a symbol used in the justification for the claim that there is a direct need to make available the merciful solution of legally hastening death for the terminally ill, with medical help and social endorsement. For

opponents of PAD, the function of stories as a speech act is to make the claim that PAD represents a social risk, a potential social problem in and of itself, because this medical practice would interact with existing social problems such as suicide, corruption, and social discrimination and would be instrumental in perpetuating and deepening social inequality and oppression. To make this claim, opponents' stories feature the symbolic code of diabetes, an illness broadly associated with chronicity and the need for ongoing medical treatment, two factors that are used to speak of the type of social vulnerability that would interact with existing social problems to generate the risk of a slippery slope for PAD legislation.

### *Social Constructionism and Public Narratives*

A constructionist approach to the analysis of public discussions on legislative matters gives us access to taken-for-granted ideas and feeling rules that circulate in the context of such discussions. Being able to tease out these ideas and feeling rules from such public discussions matters because when they materialize in institutional practices, they affect people's lives at the practical level. Such insight is facilitated by the type of qualitative analysis that narrative can provide, especially given the storytelling nature of human communication (MacIntyre 2007), and this type of analysis is possible using publicly available data. Though the stories in this analysis stem from the unique experiences of individuals, it is possible to see how their construction is void of complex details that lie outside relatable and generalizable categories (McCurdy et al. 2004) drawn from broadly shared cultural codes (Berger 1997; Swidler 1986) and feeling rules (Hochschild 1979). This finding about the composition of the narratives, in the context of a highly controversial and socially significant subject such as PAD, begs the question of how practically significant some of these neglected complex details may be. Moreover, generalized

assumptions observed in these narratives, such as the assumption that physical impairment can be worse than death, raises questions about the degree to which the narratives themselves may be supporting the discriminatory views and practices that they often are trying to fight against. This analysis demonstrates the value of publicly available data, such as public records of legislative work, for the study of cultural values and ideas, as well as of collective emotions. This study also shows how the study of stories that circulate through the social structure can affect our material lives.

Further research using a similar methodological approach could include the analysis of institutional instruments used in cases of PAD, such as request forms and documents for the consolidation of death, which could shed light on the ways in which the emotions and beliefs incorporated into the law, in places where PAD has been legalized, are set forth as institutional practices. Much could also be learned from an analysis of official annual reports on the use of PAD to understand what the institutional stories about its incorporation into the social structure are. A triangulation of analyses of different types of documents about the public discussions, which could include press articles and the narratives deployed by social movements, could also allow for the observation of the transit of cultural stories across the micro, meso, and macro levels of social life.

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## CHAPTER FIVE: CONCLUSION

The central purpose of this analysis was to explore the intersection of culture, policy, and narrative to learn about the dominant ideas and feelings that circulate in the United States regarding the legalization of physician-assisted death. Drawing from narrative theory (Fisher 1984) and narrative methods (Franzosi 1998), I sought to explore emotions in ways that would contribute to the expansion of the scholarship of emotions as cultural phenomena (Kusenbach and Loseke 2013). I specifically applied the method of multilevel narrative analysis (Loseke 2007) to the study of a policy-making process to gain empirical insight into the ways in which culturally circulating emotions can be activated through stories as political strategies (Stone 2002). I started my analysis with newspaper articles from 1997, because a search through news archives showed that 1996 and 1997 were the years when the issue had the greatest news coverage in contemporary life, a finding that was consistent with previous studies (Glick and Hutchinson 1999). Two Supreme Court cases and the histrionic activism of a doctor named Jack Kevorkian are broadly discussed in 1997's press coverage. The articles in the *New York Times* were focused on professional liability and the fundamental constitutional rights of individuals.

I then studied the participation of civil society in the debate by looking at the work of social movement organizations today and the underlying claims of their individual members as mediated by the organizations. I studied the personal stories of movement members and observed how the characters, plots, and settings in these stories revolved around the decision-making



process of the individual. The morality of the law was not observed in relation to professionals or social institutions but in relation to the individual experience of illness.

My next analysis was focused on the circulation of stories at the institutional level. I studied testimonies presented in a legislative hearing before the final vote on a PAD bill that became law in 2019. These narratives focused on the appropriateness of a solution to the identified problem of difficult deaths. The claims here were not as much about what the problem is but about what solution is required. In this context, the pragmatic communicative function of speech (Austin 1962) became a claims-making mechanism with direct influence on the social structure. These testimonies were a physical instrument in the lawmaking process.

My analysis of the broadly shared ways of thinking and feeling about physician-assisted death (PAD) in the United States drew two significant empirical findings. First, my analysis shows that the frequently observed antagonism in the positions of stakeholders in this debate (English et al. 2018) characterizes this public conversation at all levels of social life. Studies reviewed in this project have shown that Americans with a liberal political outlook are more likely to favor the legalization of PAD (Strate, Kiska, and Zalman 2001). PAD bills are mostly an effort of the Democratic Party, and although a few Democrats oppose them and a few Republicans support them, the large majority of the votes are “cleanly divided down partisan lines” (Abernathy and Covich 2020:5). However, public opinion on the issue does not seem to be as neatly divided and is possibly influenced by collective emotions and beliefs that transcend political views (Tatalovich 2020) and relate to broader moral mandates about the role of the institution of medicine, cultural views on impairment and disability, and the individual experience of health and illness.

Second, this project showed that common views on both sides of the debate remain unexplored by the literature on PAD and are largely taken for granted by participants in the public conversation. My data showed that both sides of the debate found an opportunity to open an important conversation about existing deficiencies in the health care system. Each side may address different nuances of the deficiencies, but many of the voices, regardless of their position, echoed dissatisfaction with traditional patterns in the patient-doctor relationship with regard to decision-making and grave concerns regarding health care access and allocation. For example, the stories describe medical professionals as key social actors for helping people at the end of life but also warn audiences that it is not a given that these professionals' knowledge, ability, and intentions can be trusted. Opponents of PAD describe situations when doctors may overestimate their knowledge and misdiagnose the patient, and proponents of PAD fear that doctors may make use of unnecessary technology or act driven by financial interests. To some degree, in both of these cases, the stories allude to an attitude that bioethicists have defined as medical paternalism (Fox and Swazey 2008), by which doctors may undermine or disrespect the autonomy of patients. For proponents of PAD, this paternalism can take the form of excessive, unwanted, and even torturous treatment, while for opponents, it can mean coercion to hasten one's death.

However, in spite of the critiques that the narratives make of the medical system, a common idea in both sides of the conversation is that the process of death from a terminal illness is one that must be managed by the institution of medicine. Moreover, and as has also been noted in previous studies, both sides of the debate discuss the notion of dignity (Behuniak 2011) and individual autonomy (Kalwinsky 1998), even if from significantly different perspectives. This second empirical finding highlights one of the methodological contributions of this analysis. I demonstrated how a multilevel narrative analysis can show us not only that the same cultural

narratives may be used in different levels of social lives but also that their use may have different purposes in the different contexts.

#### EXPANDING THE SCOPE OF NARRATIVE ANALYSIS IN POLICY PROCESSES

By observing narratives on a public debate in different realms or levels of social life, I have also shown how to empirically observe the circulation of cultural ideas in social life. By analyzing some of the voices in this public debate, with data beginning twenty-five years ago in mass media, social movement organizations, and legislative debates, I have expanded our understanding of what the work of stories is in our social life.

My analysis showed that the variation in the use of these cultural narratives, which contain similar ideas about the world to denote different values or emotions and to attain different goals, is an empirical demonstration of what scholars have conceptualized as culture in action (Swidler 1986). These narratives operate as tools for meaning-making because they are constructed with “deeply held, inescapable relationships of meaning that define the possibilities of utterance in a cultural universe” (Swidler 1986:282).

The following ideas about the world are examples of some of these relationships of meanings: family members love one another, hard workers are moral people, freedom generates happiness, doctors want to help, and homes are safe places. From the study of the strategic use of cultural stories like these in the definition of a problem for policy-making purposes, we can learn how collective emotions can be appealed to in different ways through variations in the distribution of cultural ideas. Different groups in different places may define different goals by using the same ideas, just differently distributed (Stone 2002). For example, the concept of liberty is central to the good death story, which is the story that promotes the legalization of

PAD. Liberty, however, is problematized by the distribution of the narratives in the slippery slope story, which is the story that opposes the legalization of PAD. In the good death story, PAD is a symbolic code for freedom. In the slippery slope story, PAD is a symbolic code for oppression.

Small changes in the distribution of the same cultural narratives alter the conceptualization of the problem in the following way. In the good death story, the narrative identity of a hardworking person or loving family member may appeal to people's compassion, for these narratives may be used to denote the loss of a capacity or a social role. Such loss may be the moral justification for choosing PAD as a way to escape a life spoiled by impairment. In the slippery slope story, a similar description of a hardworking person or a loving family member may have the function of describing normalcy and routine and thereby generate empathy. Such a need for describing normalcy is at the core of the justification for fearing PAD, since the recognition that the person's life is not spoiled by impairment is what is identified as the problem in this story.

One of the goals of this study was to observe how various types of social actors participate in policy-making processes through public debates in which they make use of cultural stories that appeal to collective emotions. This process of participation is clearly observable in the data sources incorporated in this project. I have shown how the voices of individuals representing institutional powers, such as the Supreme Court judges cited in the newspaper articles or the state representatives in the legislative hearing, participate in the debate.

Policy processes are understood as processes of simplification because they seek to find standardized solutions for highly complex social problems (Stone 2002). This makes cultural stories useful in policy-making processes because they appeal to shared emotions about popular

assumptions (Polletta 2015). The narratives I analyzed all contain individual experiences of people. The recurrence of the plots, the repeated patterns that can be observed in these stories, makes them into generalizable categories (McCurdy, Spradley, and Shandy 2004). However, their function may vary depending on the context. I have shown, by breaking down the stories into their different components, how the storytelling work of advocacy groups engages with the same general plots as the narratives in a state legislature do and also how in each context of storytelling, the narratives are used for different purposes (Loseke 2007).

To improve the policies and policy-making processes, analysts should seek to understand how social problems are being defined (Stone 2002). But how? What aspects of the definitions matter most? In this project, I observed emotions and their relation to commonly held beliefs and the experiences that people chose to talk about when debating PAD.

#### EXPANDING THE STUDY OF EMOTIONS AS CULTURAL PHENOMENA

Through this project, I showed how storytelling in public life serves as a socially prevalent tool for constructing identities and the cultural emotions associated with them (Loseke 2007, 2009, 2012, 2019). I showed, through the empirical example of a single policy-making process, how malleable our geopolitical and historically situated collective emotions can be (Stearns and Stearns 1985; Moïsi 2010). This knowledge greatly matters when we try to define what our problems as a society are, because the definitions we give to those problems will determine the solutions we will propose and implement for them (Stone 2002; Best 2008). In this study, I looked at emotional stories and treated them as a social practice (Lutz and Abu-Lughod 1992).

I worked with a number of fundamental assumptions drawn from classical theorists of the humanities and social sciences, the first being that the nature of language is arbitrary,

because the meanings in language are nothing but socially constructed symbolic associations (Saussure 2011). The next assumption was that the prescriptive systems of ideas that constitute the social norms we live by are constructed through the meanings we share through language and their appeals to emotions in social interaction and that our behaviors and attitudes are guided by these social dynamics (Elias [1969] 1994). I agree with poststructural ideas about the internalization of meanings and social norms (Foucault 1972), yet I do not focus on power differentials but instead on our use of systems of ideas by which we make sense of the world (Zerubavel 1996, 2015) and our daily behavior (Geertz 2000). I have instead focused on the selected meanings in this policy analysis in order to gain knowledge about the cultural toolkit (Swidler 1986) available to the participants in this debate. I incorporated the concept of formula stories (A. Berger 1997) to explore these selected meanings, which is to say the formulaic plots that people draw from to make sense of experience, and analyzed the ways in which symbolic codes and emotions codes—the cultural ways of thinking and feeling—were related to one another in these stories (Loseke 2009). Through the interplay of these codes, I was able to observe how stories are used as tools to establish social norms (Elias [1969] 1994), contributing to our understanding of the ways in which abstract factors such as emotions and subjective moralities affect the social structure (Berger and Luckmann 1967).

## RECOMMENDATIONS FOR FUTURE RESEARCH DIRECTIONS

This project addressed ways in which the typification of people, situations, and conditions can influence the solutions embedded in policy design. The narrative analysis of a policy process, conducted with data drawn from publicly available sources, demonstrated how we can gain

knowledge about dominant ideas on health and illness through qualitative research, constructionist approaches, and social problems theory.

Through this narrative analysis, which could be conceptualized as an analysis of speech acts (Franzosi 1998), I have demonstrated how the use of stories to explain human experience is prevalent at all levels of social life. I have also shown how specific formulaic stories explaining social phenomena circulate in culture and participate in the regulation of social relations.

Treating these stories as meaning-making tools that persuade audiences in this policy debate, and therefore unpacking the ways in which their meaning is constructed, has allowed for the recognition of taken-for-granted paradoxes in the cultural codes, which are worth unpacking even further. By “paradoxes,” I am referring to two critical findings drawn from this data analysis.

The first paradox is that both parties in the debate elaborate some form of a critique of the medical model of disability, which is the view that disability comes from a physical condition of the individual and not from the systemic barriers of the social world (Berger 2013). In the various iterations of the good death narrative, supporters construct an implicit critique of the medicalization of death and reclaim the moment of death as one that should not be experienced by default in the context of the segregated space that is symbolized by the hospital setting and the alienation felt by people in the context of the patient-doctor relationship. On the other hand, the slippery slope story is explicitly based on claims that critique the medical model of disability. A clear example is PAD opponents participating in the debate with seemingly unrelated stories about the daily activities of people with disabilities to illustrate the ideological hegemony of ableism and the danger of legalizing PAD in such a social context.

The second paradox is that both sides of the debate reproduce the broadly shared view of disability as tragedy, a view that scholars have argued is treated as “commonsense” (Oliver and Barnes 2012:121), in spite of the efforts of PAD opponents at the social movement organization level of this analysis to counter this cultural view. Given these findings, future research could expand the analysis of PAD by applying the conceptual framework of the social model of disability. Such an analysis could break down the various arguments to help uncover the shared concerns on both sides of the debate.

In this regard, a specific empirical question that emerges from my analysis is: What are the patterns of family interaction in the stories in this debate telling us about our social needs regarding end-of-life care, the general experience of illness, and the experience of disability? A theoretical question that could also be explored in relation to this subject based on my findings is: What more can medicalization theories (Conrad 2007) tell us about the construction of the bad death as a social problem? The exploration of both of these questions would benefit from a historical and comparative review of the literature on the emergence of the right-to-die movement during the 1960s, such as the work of Kutner (1969), and the literature on the sociology of death and dying that emerged in the same period (Lofland 1975). This review would provide insight into the emergence of the narrative of the overmedicalization of the dying process, which relates to the claims of a need for a social rather than medical model as an approach to the dying process.

This work has also shown how narratives remain uncomplicated and undisrupted by contradictions in their story lines to appeal to large audiences (Jamieson and Waldman 2002). This theoretical perspective can be used to tease out specific structural issues that fit the story line of one side of the debate but are ignored in narratives of the other side of the debate.



Examples are the lack of access to essential health care experienced by people with low income, noted by opponents of PAD but ignored by proponents, and the imposition of treatments classified as “not consistent with dignified end of life care,” as described by a proponent of PAD in chapter 4 but ignored by opponents. Interviews with terminally ill patients and health care providers would be an excellent source of data for this exploration.

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